



# BILLET D'ÉTAT

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14. Policy Council – The Supported Living and Ageing Well Strategy, p. 430

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## POLICY COUNCIL

### THE SUPPORTED LIVING AND AGEING WELL STRATEGY

#### 1. **Executive Summary**

- 1.1 Long-term care services in the Islands are broad in scope, but limited or under-developed in a number of key areas.
- 1.2 Information about long-term care services and how they work together is limited and poorly understood and this, coupled with deficiencies in their coordination, can impact adversely on the experiences for those Islanders in need of them. Service delivery is generally not ‘person-centred’.
- 1.3 The ability of Islanders to exercise choice about how and where they receive care and support is limited by an over-reliance on bed-based care in residential and nursing homes, and the under-development of community services and supported housing options.
- 1.4 Partly due to current funding arrangements, there is over-reliance on the States as the provider of community-based services and under-development of the third sector as a service provider.
- 1.5 Like the services themselves, the funding arrangements for long-term care have evolved in a piecemeal and haphazard manner: generating confusion for service users, limiting the development of private and third sector services, and working against the informed exercise of choice and the maximisation of personal independence.
- 1.6 The recipients of care and support are not sufficiently involved in decisions that affect them. They may also experience, however inadvertently, ageism and discrimination.
- 1.7 Carers’ needs are not well-understood or appreciated.
- 1.8 The adverse effects of loneliness need addressing.
- 1.9 Long-term care services are expensive to provide and will only become more expensive over time as the Islands’ populations age, and the incidence of older people with multiple health conditions (co-morbidities<sup>1</sup>) increases.

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<sup>1</sup> Older people are more likely to require health and social care services, and where they do require services are likely to have multiple pre-existing conditions (co-morbidities). This could for example include situations in which an older person has a fall and breaks a hip but already has diabetes, or where someone has a heart condition which requires treatment but also dementia. This combination of care needs can complicate and increase the cost of care and support provision. Due to increases in medical technology, younger adults with previous life-limiting conditions are also living longer into adulthood and old age with complex needs.

- 1.10 Neither the health and social care system nor the means by which it is funded are sustainable, and doing nothing is not an option.
- 1.11 It cannot be assumed that the issues surrounding long-term care in Alderney are the same as those in Guernsey.
- 1.12 Strategic planning to identify how best to meet future care and support needs is under-developed, and hampered by the unavailability or inaccessibility of relevant data, and a lack of skills in areas such as market development and commissioning.
- 1.13 These are the key findings of a 2-year project to develop a **Supported Living and Ageing Well Strategy (“SLAWS”)** for Guernsey and Alderney. Undertaken by a specially-constituted inter-departmental working party, the Strategy sets out four key changes that are necessary:
- A better resourced and developed strategic planning function;
  - The addressing of social attitudes towards care, disability and ageing;
  - The reconfiguration of health and social care services to provide a greater emphasis on community-based, person-centred services (including those provided to carers);
  - A radical overhaul of the funding of long-term care services and the operation of the Long-term Care Insurance Scheme in particular.
- 1.14 The Working Party’s report (see Appendix I) makes no fewer than 29 recommendations to address the issues identified by its research.
- 1.15 **The Policy Council has carefully considered the Working Party’s research and asks the States to endorse all of the recommendations outlined in its report.**
- 1.16 The Policy Letter includes a detailed and prioritised implementation plan with an *indicative* timetable to show how different elements of the Strategy could be progressed between 2016 and 2019. This identifies areas where action is recommended to be taken immediately and other areas that require additional research and/or consultation, some of which will require further consideration by the States at a later date.
- 1.17 To support its delivery, this Policy Letter outlines proposals for funding and resourcing different elements of the Strategy, the majority of which are dependent upon the allocation of funds from the **Transformation and Transition Fund**. The Policy Letter also outlines the need for appropriate governance arrangements to be established to progress the Strategy under the new political structure from May 2015.

- 1.18 Currently, around 2,000 residents of Guernsey and Alderney will be receiving some form of long-term care at any one time. Across all services and social security benefits, long-term care costs the States around £50 million per annum. Without the changes referred to above, it is projected this cost will rise to over £100 million over the next 20 years, as the number of older people (who are the largest ‘consumers’ of long-term care services) increases.
- 1.19 It is, therefore, imperative that the States commits the appropriate resources to the implementation of the Strategy, for without appropriate resourcing services will continue to be delivered as they are today, costs will continue to escalate, and individuals will be looked after, but not necessarily in the right settings, with attendant implications for their independence, health and wellbeing.

## 2. **Introduction**

- 2.1 On behalf of the Policy Council, the **SLAWS Working Party** was established in late 2013 to review the provision of long-term care and support services<sup>2</sup> provided to adults over 18 years of age in both Guernsey and Alderney. The Strategy covers all areas of long-term care, considering how best to support people who:

- live at home and who are cared for by their family or friends;
- are cared for by community services delivered into their own homes;
- are cared for through supported living options, such as sheltered and extra care housing; and
- who live in residential and nursing homes or in a hospital-based setting, or in long-term off-Island placements.

- 2.2 The Working Party<sup>3</sup> has been chaired by Deputy Harwood and formed of political representatives of the Treasury and Resources, Housing, Health and Social Services, and Social Security Departments. The Working Party has been advised and supported by staff from the Policy Council and those departments. In addition, the Working Party has tested its thinking with a **Public Engagement Steering Group**, formed of representatives of Ageing Well in the Bailiwick<sup>4</sup>, the Guernsey Disability Alliance<sup>5</sup> and the States’ Champion for Disabled People.

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<sup>2</sup> The Working Party agreed that it is the requirement for care and support by an individual that defines long-term care, not the place or situation where that care and support is provided. It encompasses a wide range of formal health and social care services, as well as the care provided by unpaid family members and other informal helpers, and is distinguishable from acute care as it is provided to individuals with enduring needs, including chronic, disabling conditions or impairments, who need help on a permanent basis.

<sup>3</sup> The Terms of Reference for the Working Party are reproduced in Appendix B of the research report.

<sup>4</sup> Ageing Well in the Bailiwick is a group brought together by the Guernsey Community Foundation which consists of representatives from organisations working with older people, from the private, voluntary and public sectors.

<sup>5</sup> The Guernsey Disability Alliance includes representatives from more than 30 local disability charities, plus individual disabled people, their families, and the professionals who support them.

- 2.3 The findings of the Working Party's research are outlined in detail in the accompanying research report, which is attached as **Appendix I**. This report describes the current provision of long-term care and support services in the Islands; the number of service users and sources of funding; and describes areas where gaps in services have been identified and where services could be improved. The research report also includes a detailed section outlining ways to fund long-term care and support in a more sustainable way to meet future demands.

### 3. **Strategic and Policy Context**

#### *Links to other areas of States' policy*

- 3.1 The Working Party's research report sets out the strategic context in which the Strategy has been developed.
- 3.2 In particular, the research report (Section 1) describes how the Strategy aligns with the States Strategic Plan and is a key part of the **Social Policy Plan**. It also highlights important links to the work of the **Disability and Inclusion Strategy**<sup>6</sup> and the **Mental Health and Wellbeing Strategy**<sup>7</sup>; in particular, in relation to the need to develop or reconfigure services where the strategies share common aims.
- 3.3 In addition to those named above, the Strategy relates to other areas of States' policy; namely:
- The Strategic Land Use Plan and the Island Development Plan;
  - The States Housing Strategy;
  - The Health and Social Services Department's '2020 Vision' for the future of health and social care;
  - The Children and Young People's Plan ("CYPP"); and
  - Planning a Sustainable Future - the Personal Tax, Pensions and Benefits Review.
- 3.4 Figure 1 which follows provides a high level summary of the strategic links that exist between this Strategy and other areas of key States' policy.
- 3.5 Although the links between this Strategy and the **CYPP** are, at first sight, less apparent than in other areas, the feedback received during the consultation processes on both strategies has highlighted the need to focus on the **transition** between child and adult services.
- 3.6 In addition, it is important to acknowledge that whatever can be done to assist Islanders to lead healthy, active and safe lives as children and young people will pay dividends in later life; in particular, it will reduce the number of people

<sup>6</sup> Policy Council – 'Disability and Inclusion Strategy' – Billet d'État XXII, November 2013.

<sup>7</sup> Health and Social Services Department – 'Mental Health and Wellbeing Strategy' – Billet d'État III, February 2013.

requiring long-term care through poor lifestyle choices. Healthy eating, exercise, and not smoking are all habits that can be established in younger years and carried through into adulthood.

- 3.7 In the new political structure, the Policy and Resources Committee will be responsible for ensuring that there is efficient and effective coordination between all these different areas of States' policy, to avoid duplication of effort and resources.







#### 4. Strategic Framework

- 4.1 Section 1 of the Working Party's report sets out the Strategy's '*Purpose*', its '*Vision*', the '*Priority Outcomes for individuals with care and support needs and their carers*', and the '*Priority outcomes for the community*'. Together, these statements set the high level strategic framework, which is reproduced below<sup>8</sup>.

##### Purpose

With regard to the care and support needs of adult (18+) Islanders to identify:

- What care and support services are needed;
- Who should provide them;
- How they should be funded.

##### Vision

To have an adaptable and continuously improving care and support system that is fair, person-centred, enabling and sustainable.

##### Priority outcomes for individuals with care and support needs and their carers:

1. **Person-centred:** to have their care and support needs considered holistically and addressed by a comprehensive, multi-sector coordinated approach rather than through piecemeal service provision and support. Care and support provision should be sensitive to the individual's context, their existing social network and relationships, interests, and life goals.
2. **Dignity, peace of mind and safety:** care services should be safe, regulated, and high quality. Support and advice should be available to those who have concerns about their own safety, dignity and wellbeing, or that of someone they care about, together with appropriate safeguarding for all 'adults at risk'.
3. **Informed and included in decision making:** all adults should be supported to exercise as much self-determination as possible, and have opportunities to make informed choices. This can range from simple day-to-day choices about what to wear, to important life decisions about where to live and who to live with.

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<sup>8</sup> The strategic framework was amended to reflect feedback received during the public consultation, to recognise more explicitly the need to balance improved outcomes for the individual with effects on the community as a whole, as set out in Section 1 of the research report.

4. **Reach health and wellbeing potential and prevent avoidable deterioration:** all adults with care and support needs and their carers should be supported to achieve the highest possible standards of physical and mental health in their day to day lives.

*Priority outcomes for the community:*

- I. **Financial sustainability and affordability of care and support in the medium to long term.**
  - II. **Strategic, evidence-based, and effective continuous development:** service development will be evidence-based, effective and respond to strategic pressures for change.
  - III. **Partnership working within and across the Islands:** a partnership culture will be established whereby the public, private and third sectors, service users, and their carers can each contribute to service delivery developments; including sharing aggregated and personal data appropriately.
  - IV. **Inclusion of all people with care and support needs in community life:** all individuals, no matter what age or disability, should be fully included in community life. Social, physical, psychological and financial barriers should be addressed where possible.
  - V. **The care sector should be a good place to work:** care staff should be supported, respected and assisted in their career development.
- 4.2 In addition to the above, Section 8 of this Policy Letter asks the States to commit to nine ‘*strategic commitments*’ necessary to ensure the effective implementation of the Strategy.

## 5. **The Review**

*Background to the research*

- 5.1 To aid the development of the Strategy, the Working Party has carried out detailed research into the wide range of long-term care and support services – in particular, within the public sector. Much time has been spent collecting and analysing data in order both to evaluate current services and to inform future policy-making and service development.
- 5.2 In addition to those persons and bodies named in paragraph 2.2, the Working Party recognises the valuable input, via consultation and other means, of a wide range of health and social care professionals, service users and others who have contributed to the development of the Strategy. The Working Party’s research

has been informed by expert advice; internal research; and public engagement and consultation; as described in detail in the Working Party's report.

5.3 Of particular note are:

- (i) the report of an external adviser, Melinda Phillips<sup>9</sup>, which identified changes that should be made to the current health and social care system in Guernsey to provide better services to Islanders; and
- (ii) a consultation document issued in June 2015 outlining the background to the Strategy, which invited comments, feedback and evidence to help guide its development. (The consultation document is available from [www.gov.gg/slaws](http://www.gov.gg/slaws))

5.4 The consultation document:

- provided an overview of existing care and support services in Guernsey;
- highlighted the challenges in delivering care and support services in the Bailiwick;
- focused on the delivery of services, the range of services provided, and the role of the public sector in service delivery;
- provided a summary of the range of issues under consideration by the Working Party; and
- discussed and offered possibilities of the ways in which services could be funded.

5.5 Over 300 online survey and written responses were received to the consultation, which ended on 22<sup>nd</sup> July 2015. A detailed summary of the findings of the public consultation document can be found at Appendix D of the Working Party's research report.

5.6 An assimilation of evidence from the Policy Council's own research; the research carried out by Phillips; the outcomes of the public consultation exercise, together with the input from the Public Engagement Steering Group; are all brought together in the research report and have been used to inform the development of the Strategy.

*Overview of the Strategy*

5.7 The Strategy recognises that the Islands' populations are ageing and that our society is changing. This is for a combination of reasons, including the fact that the Bailiwick's largest ever generation, the 'baby-boomers'<sup>10</sup>, has recently reached, and is approaching, retirement. Whilst it is good news that advances in

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<sup>9</sup> The Policy Council engaged Phillips to identify changes that should be made to the current care system in Guernsey to provide better services to Islanders.

<sup>10</sup> An explanation of this term - and all the others used in the Working Party's research report and this policy letter - can be found at Appendix A of the research report.

public health, and health and social care, mean that most Islanders are likely to live longer than their parents and grandparents and will maintain active, healthier lives for longer than previous generations, this also presents the Islands with a significant challenge. It can be predicted with some certainty that there will be more people over pensionable age and fewer people of working age in the decades to come.

- 5.8 Although not all individuals of pensionable age will give up work<sup>11</sup>, it remains a truism that because the services delivered by the States are paid for from taxes, a reduction in the working age population will result in a reduction in tax revenues; and because older people are more likely to have long-term care needs, the cost of delivering services will increase while the funds available to pay for them will decrease. This demographic change – which is already upon us - has wide reaching implications for our community, our economy, and our government, and is one of the primary drivers behind the need to develop this Strategy.
- 5.9 In its research, the Working Party focused on reviewing existing services and identifying any shortfalls or deficiencies in provision or service delivery. This was achieved by carrying out an audit of existing services to understand better the number of individuals accessing care and support; the costs attached to different elements of the current system; and their present funding mechanisms. The Working Party also engaged external assistance to help identify gaps in provision and consulted widely within the Islands to understand better where improvements can be made.
- 5.10 Although primarily focussed on service provision, the Working Party's research identified that attention needs to be given to the more subtle ways in which social attitudes can affect the lives of people with long-term care and support needs. The needs of carers have also been identified as a priority for attention, Guernsey being the only member of the British Irish Council not to have a dedicated Carers' Strategy.
- 5.11 Islanders have consistently voiced the opinion that, given the choice, the majority would prefer to receive long-term care and support in their homes (or in a supported housing environment) rather than in a residential home. However, although this has been known for many years and some efforts have been in recent times to develop supported housing options – the extra care housing at Le Grand Courtil and La Nouvelle Maraitaine being prime examples - the Working Party found that whilst there are services that are available to support people living in the community, these are relatively under-developed. Instead, the health and social care system continues to place a greater emphasis on high intensity bed-based provision of care. While residential care will continue to have its place - albeit that it probably needs to become more specialised - the current bias towards institutional care needs to be rebalanced by improving the

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<sup>11</sup> And many will contribute to society in other ways, whether through volunteering or caring for relatives.

availability of care in the community in its various forms, (though all forms of care are likely to need to expand in coming years to cope with increasing demand).

- 5.12 As the Islands' changing demographic profile begins to place heightened pressure on the funding of services at a time of increasing demand, the research report looks extensively at ways to fund sustainably the provision of a full range of long-term care and support services in the future. Ways to mitigate against increasing long-term costs are identified, and the report advocates the value of investing in preventative measures to help contain future escalating costs, wherever possible.
- 5.13 Throughout, the Working Party's report recognises the need to balance improved outcomes for the individual with the effects on the community as a whole. In particular, the Working Party identifies the need to rebalance what is paid for by the States and what is paid for by the individual receiving care. Hence the overall Vision: **to have an adaptable and continuously improving care and support system that is fair, person-centred, enabling and sustainable.**

*How changes in service delivery can benefit service users and their carers*

- 5.14 Boxes 1a and 1b which follow include a fictional example which sets out two very different models of service provision, and shows how the more integrated model of care espoused by this Strategy (described in Box 1b) has positive benefits for improving the day-to-day quality of life of both the individual with long-term care and support needs and the person who cares for them.
- 5.15 This idealised example is not intended to describe existing provision in the Islands or to prescribe ways to enhance existing services.

### ***Box 1a. Harry and Edith***

***Harry (79) and Edith (77) live in an old Guernsey cottage in St Peter's where they moved after they got married. Their son (Mark) and daughter (Karen) have both moved to the UK where they are settled and cannot come back frequently.***

#### *Scenario one:*

In 2010, Harry was admitted to hospital after a fall. When Harry was fit to be discharged he was sent home, but no one enquired about whether Edith would be able to cope looking after him. Since he was struggling with the stairs, Edith arranged to move the bed into the sitting room. Whilst there was a toilet downstairs which Harry could get to with a bit of help, the bathroom was up stairs and Harry was reluctant to attempt to climb them. Harry depended on Edith to help him wash, go out, drive, do the shopping, cook, and do any lifting or carrying.

Whilst Edith had been a regular attender at W.I. meetings and enjoyed playing euchre with friends, she did not like leaving Harry on his own in case he fell again, so increasingly she stopped socialising to care for Harry.

Edith had been feeling stressed, anxious and down, and went to see her General Practitioner who gave her anti-depressants and diagnosed her with high blood pressure. Whilst the General Practitioner helped with her health, he did not ask how she was coping with caring for Harry.

Earlier this year whilst Edith was out doing the grocery shopping, Harry had another fall. He ended up in hospital again and was no longer able to stand up on his own easily. Harry was discharged home, as Edith was insistent that she could cope with looking after him. However, Edith became unwell and their daughter Karen, who was concerned, flew over to help.

Karen contacted community services for help. When they undertook an assessment they found that Edith was no longer able to go out to the shops or get Harry out of bed, and that caring for him was having a detrimental impact on her health. The house was not suited to adaptations such as hoists, which would help Edith to care for Harry. A social worker assisted in finding a place for Harry at a residential care home and Edith now visits him regularly.

Fictional illustration inspired by 'Two different stories of caring' from the National Collaboration for Integrated Care and Support (2013) *Integrated Care and Support: Our Shared Commitment*, Available at:

<https://www.gov.uk/government/publications/integrated-care> [accessed 30/11/15].

### ***Box 1b. Harry and Edith***

***Harry (79) and Edith (77) live in an old Guernsey cottage in St Peter's where they moved after they got married. Their son (Mark) and daughter (Karen) have both moved to the UK where they are settled and cannot come back frequently.***

In 2010, Harry was admitted to hospital after a fall. When Harry was fit to be discharged a member of the discharge team undertook a carer's assessment to talk to Edith one-to-one about how she could cope with caring for Harry. It became clear that there would be some difficulties for Edith caring for Harry in their current cottage. After this they met with Edith and Harry to discuss what support she might need to look after him at home. Edith and Harry were offered a short-term placement in an extra care flat with a programme of physiotherapy to help Harry to regain his confidence in moving around the flat. Within the flat, with the aid of some equipment, he was able to prepare himself basic meals, get out of bed, and shower by himself. He could even go down to the café in the extra care housing complex.

After a week living in an extra care flat, Harry and Edith saw the potential benefit of changing their environment and decided that they may need to consider moving house to somewhere which was more accessible.

Karen came to help Edith with preparations; and the staff at the extra care scheme directed them to a helpful information service, website and booklet which outlined the available options. Staff at the information service talked through the options with them. Since Harry was now mostly self-sufficient, they decided that they didn't yet need to be in an extra care facility permanently and looked instead at sheltered housing. Edith and Harry found an accessible flat in a sheltered housing complex and Karen helped them to move house.

Through the information service they found out about some services that could help them: they had a 'Lifeline' telecare system fitted, so Edith could go out and know that if Harry fell again he would be able to call for help easily; Edith also undertook a course on using an iPad and learnt how to SKYPE Mark and Karen. Edith and Harry knew some of the other people who lived in the sheltered housing complex and they met with them regularly for meals, games and outings. Harry knew that he could ask his neighbours for help if he needed to without having to go outside or tackle any steps.

When Edith was diagnosed with high blood pressure her General Practitioner's surgery provided her with information on a walking for health group, she was visited by a Health Visitor to help her to plan her diet, and her health started to improve again.

After his physiotherapy Harry remained reasonably active and confident, but he still struggled with going out shopping on his own, and lifting and carrying heavy items. When Edith went down with a bad chest infection the General Practitioner came to visit and asked Harry and Edith how they were coping. The General Practitioner referred Harry and Edith to community services for some temporary support with shopping, hot meals and getting Edith out of bed in the morning. Edith recovered, and she and Harry were able to remain living in their apartment.



Key areas of the Strategy

5.16 The Working Party has put forward a raft of recommendations in response to its findings, which are designed to facilitate wholesale changes to the ways in which services are currently delivered to provide person-centred care. It identifies major service improvements to ensure that the services are more *customer-focussed, efficient and sustainable* for the future.

5.17 **The Working Party believes that in order to align provision with the strategic direction identified and outlined in its report, significant changes need to be achieved in the following four key areas:**

- 1) **Enhancing resources to plan effectively how to meet the needs identified by the Strategy and to develop effective partnerships with the private and third sectors** (*Section 3 of the research report*)

*“We are glad that the Strategy acknowledges from the outset that there will be a need for real partnerships between the States, the private sector and the voluntary sector if major change is going to be achieved. Our members have emphasised that their relationship with the States does not feel like real partnership at present – there is a lack of information-sharing and involvement in service planning. This will need to change considerably in order for partnership working to be effective.”<sup>12</sup>*

**Ageing Well in the Bailiwick**

*The States of Guernsey should take a strategic role in developing a “care community” working in partnership with the private and third sectors. This will involve effective data gathering and analysis; providing information to the public; regulation of care services; analysis and development of the relationship between different services in order to improve coordination; and effective linking with other key areas of strategic policy.*

The relationships between the States, the private sector, the third sector, and carers are complex – forming a network of provision for individual Islanders. How the different organisations and people involved in the ‘care community’ work together is key to effective and efficient service delivery.

The Working Party has identified that there is an absence of strategic oversight in the ways that services work together: to develop the capability to model and project need levels, and to initiate and coordinate change, not only across the States but also with the private and third sectors. To address this, the Working Party recommends that a strategic planning function should be established to support the effective

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<sup>12</sup> This quotation was in response to the public consultation.

implementation of the strategic planning, market development, and commissioning aspects of the Strategy.

**2) Addressing a range of societal issues affecting attitudes towards those with care and support needs (Section 5 of the research report)**

*“Staff talking to elderly residents as if they are small children rather than intelligent adults who just happen to be a bit older is one of my bugbears. It happens far too often. I tell them frequently that I may be old but that doesn't mean I'm stupid.”*

**Respondent to the public consultation**

*Attention must be given to addressing ageism, and ensuring disabled people and their carers are socially included. Community approaches to loneliness should be explored. It is important that care and support is enabling and supports people to live meaningful lives and that care and support are not seen as simply doing things for people.*

In a Strategy of this nature, it would be easy to focus on the obvious areas of service provision and funding, and to neglect the less tangible issues about how individuals are treated by society and by those who deliver health and social care services. To avoid this, the Working Party report recommends that attention needs to be given to the more subtle ways in which societal attitudes and assumptions affect people's lives, and how community expectations can limit their opportunities.

It also advocates: considering ways to address loneliness; and ensuring that attitudes within the care sector focus on maximising the independence of people with care and support needs.

**3) Focusing on a number of areas where services can be reconfigured (Section 6 of the research report)**

*“I have been a carer for less than a year. During that time no-one has discussed any of the types of respite care with me. I was not aware that they were available. I feel angry and frustrated that these services were not made known to me or the person I care for.”*

**Respondent to the public consultation**

*The Working Party's research has identified that services need to be developed in all areas including care homes, supported living services and care in the community. However, areas for immediate priority action should include expanding support for informal carers<sup>13</sup> (including short-break services); establishing a re-enablement service to help people to regain independence after being admitted to hospital; and establishing a*

<sup>13</sup> 'Informal care' refers to the unpaid care and support provided by family and friends.

*proactive care coordination service where a single point of contact can case manage an individual's care where they are receiving care from multiple providers, in order to ensure that the approach is effectively joined-up and that individuals are aware of all of the services open to them.*

To achieve the above will not only require changes to the ways in which individual services are provided, but will also necessitate detailed consideration about the ways in which services can become better coordinated and integrated to support the delivery of high quality 'person-centred' care. As described, this is predicated on a major shift in provision, away from the current emphasis upon care being delivered in institutional bed-based environments which engender dependence, towards independence, with care and support being delivered in community settings, wherever possible.

In particular, of fundamental importance to the delivery of this part of the Strategy will be the wider transformation of health and social care (see Section 8 of this Policy Letter); to ensure that care and support services become better aligned to meet peoples' needs; to improve the availability and range of care in the community, with a renewed focus on services that promote 're-ablement' of individuals following a crisis event or period of time in hospital; and for there to be a wider availability of supported living options.

**4) Addressing the strategic funding issues, in particular, taking action to improve the sustainability of the Long-term Care Insurance Fund**  
(Section 7 of the research report)

*"I am disabled with a genetic progressive illness and I do not want to be one of the elderly people left to sleep in a chair all day in a home and charged handsomely for the privilege. Why can't we stay in our homes with our friends around us in an area we are happy."*

**Respondent to the public consultation**

*The funding structure should be sustainable and should balance the mitigation of financial risk to the individual against the tax burden on the wider community. A three-stage approach is recommended by the Working Party: firstly, by increasing Social Security contributions by at least 0.5% from 1<sup>st</sup> January 2017; secondly, by increasing an individual's long-term care co-payment for residential and nursing care (in order to cover their living and accommodation costs); thirdly, by expanding the scope of the Long-term Care Insurance Scheme to allow Long-term Care Benefit to be used to purchase domiciliary care in individuals' own homes and in supported housing options, together with exploring the possibility of introducing personal budgets. The Working Party also recommends that, throughout this process of reform, further*

*measures to make the system financially sustainable should be kept under review, including the possible inclusion of capital assets in any means-testing of benefits and the possible capping of the amount of care costs to be funded by the States.*

The Working Party has carried out detailed research to understand better the strategic issues associated with developing a long-term sustainable funding system that is able to support the anticipated increased requirement for care and support services in the Islands in decades to come. It is clear from the Working Party's research that **continuing to fund the provision of long-term care to an ageing population using current funding models will be financially unsustainable in the long-term.**

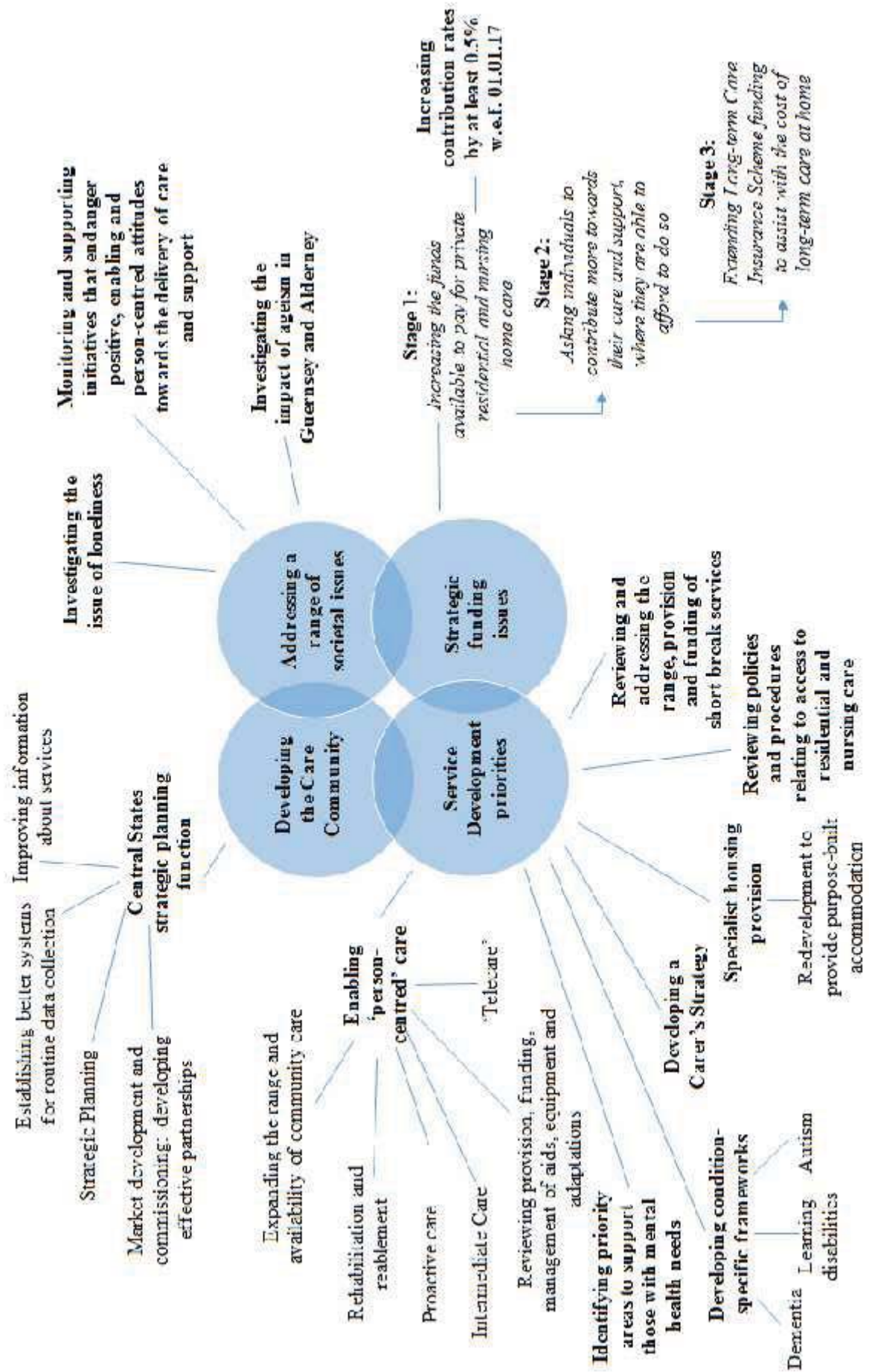
There is an imperative to reform existing systems, not only because the current funding system is unsustainable, with the Long-term Care Insurance Fund (which is only part of the system) due to run out of money within the next 15 to 20 years, **but also because it is believed that a fairer system, which provides more choice and empowerment, is achievable.**

Funding models must be altered if the Islands are to cope with this unprecedented level of demographic change. **To do nothing would see existing funding sources exhausted, would restrict the care options available to people, and would prove to be a very expensive option for all involved.**

An incremental, three-phase approach to tackling the funding issues is described by the Working Party and endorsed by the Policy Council: the most immediate of which recommends that the Committee for Employment and Social Security be asked to bring forward proposals to increase contribution rates to the Long-term Care Insurance Fund for employed, self-employed and non-employed persons by no less than 0.5%, with effect from 1<sup>st</sup> January 2017. **This measure will enable reserves to be built within the Fund in the short-term, to help meet its future obligations; it will also act as buffer while the other measures to reform the delivery of health and social care services are worked through and further actions to change long-term care funding arrangements are planned in more detail. In itself, however, such an increase in the level of contributions does not address the long-term funding issues identified by the Working Party.**

- 5.18 A summary overview of the Strategy and the workstreams associated with the four key areas described above is shown in Figure 2.

Figure 2: The Strategy on a page





## **6. Meeting the long-term care needs of Alderney and its residents** (Section 4 of the research report)

*Although the Islands are closely linked, the research informing the development of the Strategy has identified some important differences between Guernsey and Alderney, which need to be taken into account to provide an effective Supported Living and Ageing Well Strategy to Alderney residents.*

6.1 Whilst the purpose of the Strategy and its proposed outcomes should be the same regardless of the Island in which someone is resident, the consultation process identified some issues that are specific to Alderney that may need special consideration. These issues include:

- The remoteness of Alderney and the challenges this presents for service delivery;
- How the States of Guernsey, States of Alderney, private and third sectors can work together to support people in Alderney with long-term care and support needs;
- How to improve services at times of transition, for example from hospital to home;
- Travel for appointments, and allowances for passengers accompanying patients to such appointments;
- The restricted availability of services and the opportunities to improve service delivery, including consideration of the use of innovations, such as ‘telecare’<sup>14</sup> and ‘telehealth’<sup>15</sup>;
- Clarifying the responsibilities between the States of Guernsey and States of Alderney, especially with regard to strategic planning; and
- The availability of data about services and needs relating to Alderney.

6.2 In order to take all of the above into account, the Working Party recommends that a dedicated piece of work is required to understand better the needs and requirements of Alderney residents.

## **7. Implementation and governance**

7.1 The Policy Council has carefully considered the Working Party’s research and supports all of the recommendations in its report.

7.2 It acknowledges that some of the workstreams identified are at the stage where a specific course of action is recommended, whereas other areas require additional research and consultation. Accordingly, the Policy Council is asking the States:

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<sup>14</sup> Technology which allows for people to call for help and allows certain warning signs to be monitored remotely.

<sup>15</sup> Technology which allows people to communicate with health professionals who are in different locations.

**To endorse all of the recommendations to progress the Supported Living and Ageing Well Strategy, as set out in the Working Party's research report and reproduced in Appendix III.**

- 7.3 **Appendix II** to this Policy Letter provides a detailed *indicative* timetable for implementing the Strategy's recommendations between 2016 and 2019. It shows that there are multiple workstreams and actions to be progressed, with various different timelines for reporting back to the States of Deliberation and to the Policy and Resources Committee, which will require effective cross-committee working if they are to be achieved successfully.
- 7.4 **However, their achievement is entirely dependent on funding and associated staff resources being in place to undertake research, planning and service development.**
- 7.5 In its report on Public Service Reform (Billet d'État XVI, September 2015), the Policy Council advised that: *'At present, there are insufficient staff with the appropriate skills to support the timely co-ordination, development, and implementation of government policies.'* Indeed, the Reform Framework itself highlighted that: *'Too often, problems arise when policies are affected by over ambitious timeframes, a lack of resources, and poor risk management.'*
- 7.6 The Policy Council acknowledges that the level of transformational change proposed by this Strategy will require:
- (i) existing resources to be deployed in different ways;
  - (ii) the allocation of additional resources in areas where there is a particular shortage of skills; and
  - (iii) the various workstreams identified to be resourced and managed as a programme of projects – in this instance, primarily as part of the wider transformation of health and social care (see Section 8 below).
- 7.7 **At the time of writing, the necessary resources are not in place and only the actions highlighted in Appendix II can be taken forward with existing resources. Therefore, it would not be sensible to ask the States to commit to a number of significant actions that are neither resourced nor funded. This would be simply committing those charged with various actions to failure.**
- 7.8 Furthermore, the States of Guernsey is due to experience a major change in government structures, combined with the election of a new States of Deliberation. The new Assembly will need, early on in its life, to determine its priorities for the new term and to enshrine these in a new States Strategic Plan and Government Service Plan.
- 7.9 It follows that, at this point in time, it cannot be said with any certainty what priority will be awarded this Strategy or any of its component parts and, therefore, what resources and funding will be devoted, if any, to its delivery.



- 7.10 In addition, the Policy Council is reluctant to set in stone what governance arrangements should apply, believing this to be a matter for the new Policy and Resources Committee to determine in due course. Nonetheless, the Policy Council considers that this Strategy, plus the other major social policy strategies identified in Section 3, would benefit from having dedicated oversight from one or more of the members of the Policy and Resources Committee to ensure that they are effectively coordinated and implemented.
- 7.11 All of the above leads the Policy Council to make the following recommendations to the States:

**To direct that, until alternative arrangements are agreed, the Policy Council – and thereafter the Policy and Resources Committee - shall be responsible for ensuring that the Strategy continues to be taken forward.**

**To direct the Policy and Resources Committee, as part of the finalisation of the Policy and Resource Plan, to report to the States, no later than July 2017, on the arrangements by which political direction and oversight will be provided to enable the Working Party's recommendations to be progressed and implemented, having first consulted with the Committees for Health and Social Care, Employment and Social Security, and Environment and Infrastructure, together with the States of Alderney and appropriate third sector groups.<sup>16</sup>**

**To approve, in principle, the implementation plan and timescales associated with taking forward the various elements of the Strategy, as shown in Appendix II, but to ask the Policy and Resources Committee to bring forward firm proposals as part of the aforementioned report, including identification of the resources required.**

**To acknowledge that to bring about the level of transformational change identified by the investigations undertaken to date will require significant further research and other implementation activities that can only be undertaken successfully by applying to them programme and project management disciplines, and by assigning to them the right level of appropriately skilled resources.**

- 7.12 Finally, in order to monitor progress on the implementation of the actions identified, the Policy Council considers that the States should be asked:

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<sup>16</sup> The report of the States Review Committee – *'The organisation of States affairs – third Policy Letter'* (Billet d'Etat XXI, November 2015) - set out how the new Policy and Resource Plan should be developed and the associated timescale. The report describes that in June 2017 the States will debate and make resolutions on the Principal Committees' policy plans and ultimately finalise the content of the Policy & Resource Plan Phase 1 and Phase 2. Further proposals to progress this Strategy will need to take place within this broader policy planning process.

**To direct that progress on implementing the actions in the Strategy form part of the annual reporting on the Policy and Resource Plan that will commence in June 2018.<sup>17</sup>**

**8. The Supported Living and Ageing Well Strategy: Part of a wider agenda of public service reform and Health and Social care transformation**

*‘A Framework for Public Service Reform’*

- 8.1 In September 2015 (Billet d’État XVI, September 2015), the States of Deliberation endorsed a ten-year framework for transforming the organisation, management and delivery of public services in Guernsey.
- 8.2 **‘A Framework for Public Service Reform 2015-2025’<sup>18</sup>** seeks to ensure that public services: are focused on customer needs; act in partnership as one organisation with common purpose and in partnership with outside expertise; are organised and delivered in ways that centred on those who use them; and public resources are used wisely and carefully. All of these aims resonate strongly within this Strategy.
- 8.3 For example, the Framework aims to foster an environment within public services that embraces innovation and continuous improvement. It also describes the need to use information to drive performance and to inform longer-term transformational objectives. This has strong links with the Working Party’s proposal to establish a strategic planning function as part of this Strategy, to gather information and monitor needs within the care sector, and to establish systems for improved routine data collection (as referred to in Section 5 of this Policy Letter).
- 8.4 Similarly, the Framework acknowledges that the third sector<sup>19</sup> has a wealth of knowledge and expertise that can inform policy development as well as service delivery. Working with the private and third sectors on policy and service development will become the norm, rather than the exception, in order to provide the best outcomes for the community, and this has been a key area in the development of this Strategy to date.
- 8.5 Public Service Reform also makes a commitment to free up resources by making existing processes more cost-effective and efficient, with the resources saved being reinvested in new or improved services to meet increasing demand, and ensuring that they are sustainable into the future. The progression and implementation of this Strategy is heavily dependent on the achievement of this

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<sup>17</sup> This is in accordance with how the new Policy and Resource Plan should be monitored, as set out in the report of the States Review Committee – *‘The organisation of States affairs – third Policy Letter’* (Billet d’État XXI, November 2015).

<sup>18</sup> States of Guernsey - *‘A Framework for Public Service Reform 2015-2025’* - available from [www.gov.gg](http://www.gov.gg) (accessed on 21<sup>st</sup> October 2015).

<sup>19</sup> The term ‘third sector’ includes charities, voluntary groups and non-governmental organisations.

‘reform dividend.’ (As an example, Section 6.3.1 of the Working Party’s research report explains the positive financial and other benefits of introducing re-ablement services.)

### **The Transformation and Transition Fund**

- 8.6 The **Transformation and Transition Fund** was created to enable the type of transformational change outlined in this Strategy, recognising *“the significant investment required to deliver the public services of the future and the substantial policy agenda for the States.”<sup>20</sup>*
- 8.7 To access the Fund, programmes and projects are required to demonstrate:
- significant long-term transformation in the delivery of services;
  - evidenced and measurable benefits; and
  - a return on investment (a ‘reform dividend’).
- 8.8 In the 2016 Budget Report (Billet d’État XIX, October 2015), it was reported that the Policy Council and the Treasury and Resources Department considered that *“given the level of bids [for use of the Fund] and the uncoordinated nature of the proposals received, investment at this stage should be restricted in order to ensure that plans are properly developed and benefits considered”* before approval to proceed with individual initiatives was sought.
- 8.9 However, of specific relevance to this Strategy, the States agreed to prioritise for funding from the Transformation and Transition Fund:
- **Social policy development** (to ensure that SLAWS and other social policy development was appropriately resourced to initiate and coordinate corporate change);
  - **The programme for transforming health and social care services.**
- 8.10 The Treasury and Resources Department has been given delegated authority to approve funding of up to £750,000 for any one programme, or £1 million in respect of transforming health and social care services. Upon receipt of an appropriately detailed business case or resource request, these monies can be released to enable suitably defined project proposals to be drawn up.

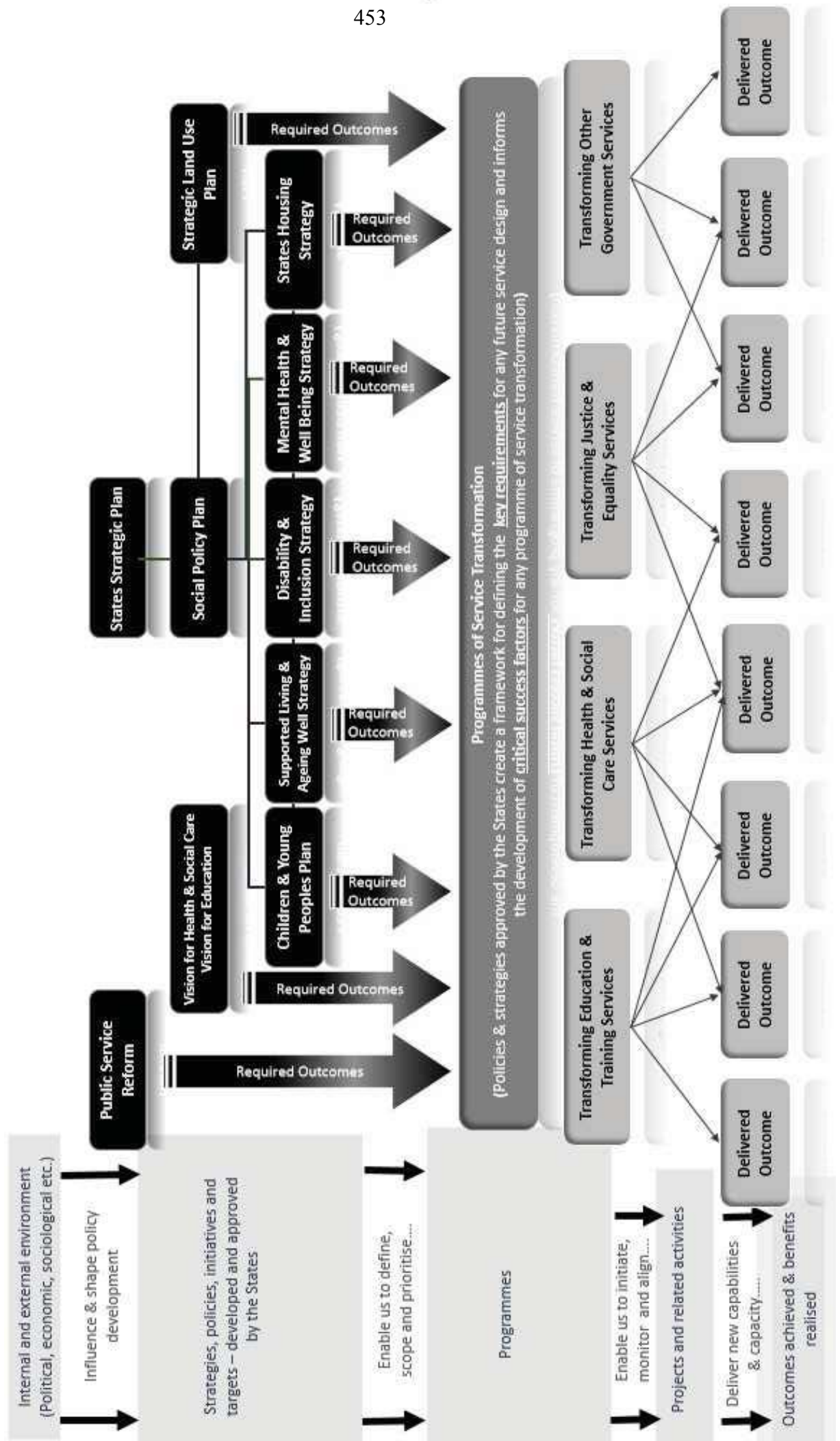
### **Progressing specific recommendations**

- 8.11 As noted above, the indicative implementation plan for this Strategy sets out a mixture of further policy research and specific operational changes, each of which will need to be resourced and funded through the process described above. This is illustrated by Figure 3, which shows the SLAWS is one of a number of strategies to be taken forward through Public Service Reform and its associated programmes of service transformation.

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<sup>20</sup> ‘Annual Budget for the States for 2016’ - Billet d’État XIX, October 2015.

Figure 3: Delivering social policy objectives through the Public Service Reform



*Social Policy development*

- 8.12 The Policy Council will be seeking funding to provide additional resources to focus on strategy coordination, strategic planning, market development, and commissioning, in order to help to initiate and coordinate cross-departmental and cross-sector change to support the further development and implementation of this and associated strategies, i.e. the Disability and Inclusion Strategy, the Mental Health and Wellbeing Strategy, and the CYPP.
- 8.13 This may also provide the resource to lead the work on loneliness and ageism and to develop a Carers' Strategy.
- 8.14 Given that ensuring co-ordination of the Strategy, and gathering data to inform high-level decision-making, is critical to delivering the entire work programme, the Policy Council is, in anticipation of a positive decision from the States on this issue, undertaking preparatory work in order to ensure that this action can be delivered swiftly by whatever body is responsible for the function in question once approval is obtained. Therefore, rather than awaiting a decision and then starting to act on it, the time between submission of the policy letter and the relevant States' debate is being put to good use in terms of advancing work on this key enabler.
- 8.15 It is acknowledged that there are risks in this approach in so far as work could turn out to have been abortive if it is decided not to pursue or prioritise this work stream. However, this risk is considered low, given that co-ordination of service delivery is so crucial to the success of the Strategy. The Policy Council also believes that this demonstrates its absolute commitment to advancing the entire Strategy.
- 8.16 In very broad terms, an indicative outline project plan for this aspect of the Strategy has been produced, as set out below.

| <b>Action</b>   | <b>Completion Date</b> |
|---|------------------------|
| Scope the services to be provided by the strategic planning function  | 15 January 2016        |
| Determine resources needed to provide strategic co-ordination function.   | 31 January 2016        |
| Draft job descriptions for any new roles required   | 31 January 2016        |
| Draft business case for strategic co-ordination function  | 15 February 2016       |
| States' decision  | 19 February 2016       |
| Refine business case if necessary and submit to Treasury & Resources  | 26 February 2016       |
| Treasury & Resources decision   | 15 March 2016          |
| Assuming Treasury & Resources approval obtained, start recruitment process for any roles that cannot be covered by reorganisation of existing resources | 29 March 2016          |
| Successful candidates start   | 15 June 2016           |



- 8.17 As acknowledged above, these time scales are indicative and are based on what is currently known. Should it prove possible to deliver more quickly, then that opportunity will be taken. Equally, it may prove that a little more time is needed. Either way, the Policy Council is optimistic that this proactive approach will enable it to ensure that the strategic planning function is operational at the very earliest opportunity.

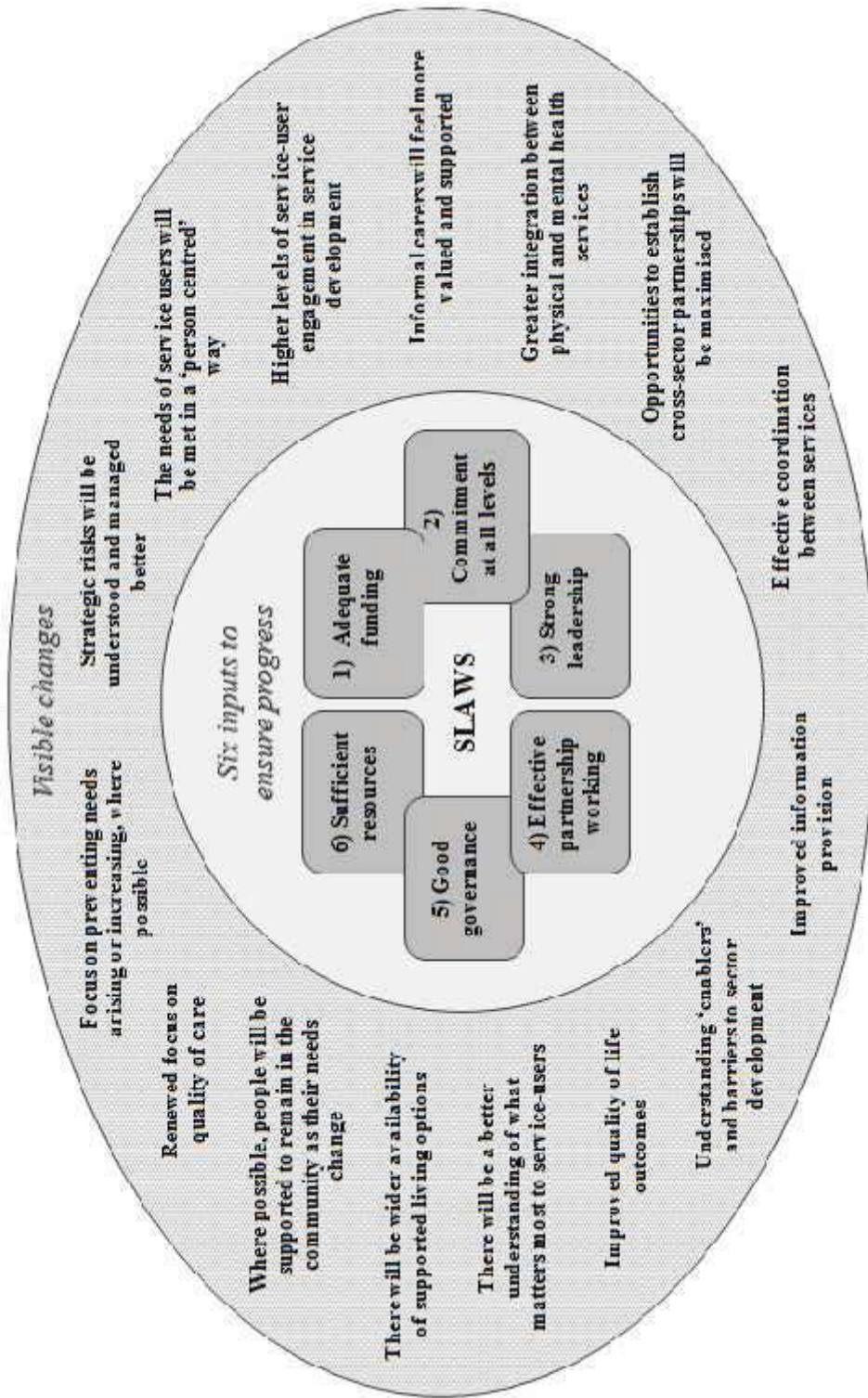
*Programme for transforming health and social care services*

- 8.18 The Housing, Health and Social Services, and Social Security Departments (and their successor Committees) will need to work together to design and resource the **programme to transform health and social care in Guernsey and Alderney**, of which many of the actions in this Strategy will need to form a part, albeit it is anticipated that those workstreams associated with the review and scope of the Long-term Care Insurance Fund will be paid for from monies in that Fund.

*Investigating the use of social finance*

- 8.19 As part of the Health and Social Services Department's Policy Letter on the CYPP, the States of Deliberation will be recommended to direct the Policy and Resources Committee to oversee and coordinate an investigation into the use of alternative sources of social finance. If this recommendation is accepted, then that investigation should also include the use of social finance as a means of funding the service delivery changes necessary to implement this Strategy.
- 8.20 Figure 4 overleaf shows the six key inputs required to progress the Strategy and the visible changes that are expected as a result of investing in the transformation described above.

Figure 4: Key inputs and expected changes arising from transforming service delivery as part of the Strategy





## 9. Political Commitment to the Strategy

- 9.1 The development of SLAWS has had a long and somewhat chequered history and, therefore, its publication will be much anticipated. At the time of writing, **much work has already begun in relation to its implementation; for example, the Health and Social Services Department has started preparing proposals for re-ablement services, and is looking at aids and adaptations issues, and the benefits of telehealth and telecare.** Nonetheless, the Policy Council considers that, to demonstrate the States' intent to progress the Strategy, it should be asked:

**To make nine strategic commitments required to bring about the significant transformational change necessary to deliver the Strategy.**

- 9.2 The proposed strategic commitments are as follows:

- *We will develop our role as a strategic planner and facilitator in the development of a multi-sector network of care and support providers. This will include working closely in partnership with the third and private sectors, and improving and appropriately sharing our aggregated and personal data.*
- *We will develop working practices, housing provision, benefits, and service structures to meet the holistic needs of service users in a person-centred way.*
- *We will work to address all forms of discrimination and unhelpful attitudes about care and support.*
- *We will promote inclusion and meaningful, enabling care and support provision.*
- *We will provide and communicate information and help people to make informed decisions.*
- *We will recognise the value of informal carers and seek to ensure that they are supported.*
- *We will recognise the importance, needs and value of the care sector and those who work in it.*
- *We will ensure that there is a sustainable funding system in place.*
- *We will ensure that everyone can afford to access the care and support they need.*

## **10. Consultations**

- 10.1 As described in this Policy Letter and in the accompanying research report, the Strategy has been prepared in consultation with a number of States' departments and stakeholder groups, and has been informed through public engagement and consultation.
- 10.2 The Law Officers of the Crown have also been consulted.

## **11. Good Governance**

- 11.1 The Policy Council considers that the six principles of good governance have been complied with in preparing this Strategy for consideration by the States.

## **12. Conclusions**

- 12.1 This Policy Letter has provided a high level overview of the research carried out by a Working Party that was established to review all long-term care and support services provided to adults in Guernsey and Alderney.
- 12.2 The Strategy provides a framework for co-ordinated, cross-sector action to provide for the long-term care needs of the two Island communities. Significant transformational changes are required both in the ways in which services are delivered and how they are funded.
- 12.3 The need for these changes has been identified before, but they become more and more essential with each passing year: they cannot continue to be put off. Already, around 2,000 residents of Guernsey and Alderney will be receiving some form of long-term care at any one time, at a cost to the States of around £50 million per annum; the number of such recipients will continue to increase as the Islands' populations progressively age. Making no changes to the ways in which services are provided or funded will mean that the projected cost to the States will double in 20 years and quadruple in 40 years. This is an unsustainable position.
- 12.4 Where it is possible for work to be progressed in line with the Strategy with existing resources, this will be done as soon as is practicable. However, much of the change that is required cannot be carried forward without investment. It is, therefore, imperative that the States commits the appropriate resources to the implementation of the Strategy, for without appropriate resourcing services will continue to be delivered as they are today, costs will continue to escalate, and individuals will be looked after, but not necessarily in the right settings, with attendant implications for their independence, health and wellbeing.

### 13. **Recommendations**

#### 13.1 The Policy Council recommends the States:

- (i) To endorse all of the recommendations to progress the Supported Living and Ageing Well Strategy, as set out in the Working Party's research report and reproduced in Appendix III;
- (ii) To direct that, until alternative arrangements are agreed, the Policy Council – and thereafter the Policy and Resources Committee - shall be responsible for ensuring that the Strategy continues to be taken forward.
- (iii) To direct the Policy and Resources Committee, as part of its finalisation of the Policy and Resource Plan, to report to the States, no later than June 2017, on the arrangements by which political direction and oversight will be provided to enable the Working Party's recommendations to be progressed and implemented, having first consulted with the Committees for Health and Social Care, Employment and Social Security, and Environment and Infrastructure, together with the States of Alderney and appropriate third sector groups;
- (iv) To approve, in principle, the implementation plan and timescales associated with taking forward the various elements of the Strategy, as shown in Appendix II, but to ask the Policy and Resources Committee to bring forward firm proposals as part of the aforementioned Policy and Resource Plan, including identification of the resources required;
- (v) To acknowledge that to bring about the level of transformational change identified by the investigations undertaken to date will require significant further research and other implementation activities, which can only be undertaken successfully by applying to them programme and project management disciplines, and by assigning to them the right level of appropriately skilled resources;
- (vi) To make the nine strategic commitments required to bring about the significant transformational change necessary to deliver the Strategy; and
- (vii) To direct that progress on implementing the actions in the Strategy form part of the annual reporting on the Policy and Resource Plan that will commence in June 2018.

J P Le Tocq  
Chief Minister

G A St Pier  
Y Burford  
D B Jones

P L Gillson  
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M G O'Hara

R W Sillars  
P A Luxon  
S J Ogier

7<sup>th</sup> December 2015

A H Langlois  
Deputy Chief Minister



**Appendix I: The Working Party's research report on the Supported Living and Ageing Well Strategy**

# Research Report for the Supported Living and Ageing Well Strategy (SLAWS) 2016

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prepared by the SLAWS Working Party

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## Executive Summary

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The Supported Living and Ageing Well Strategy focuses on adults (18+) with enduring care and support needs. This includes, but is not limited to, services for people with physical and sensory impairments, chronic illness, neurological conditions, stroke survivors, autism, learning disabilities, dementia, conditions associated with ageing and enduring mental health conditions. It covers the full range of services from those provided to people living at home who are mostly self-sufficient or are cared for primarily by a family member; to community services, extra care housing, residential and nursing care homes, specialist care at the Duchess of Kent or Lighthouse Wards, and off-island placements.

A Supported Living and Ageing Well Strategy (SLAWS) Working Party was formed by the Policy Council's Social Policy Group in November 2013. The Working Party has set out to examine what services should be provided to adults (18+) with enduring care and support needs, to consider who should provide care and support services, and how they should be funded.

Guernsey and Alderney face significant challenges in coming years. There is identified need for improvement in the current system, over which there is little strategic oversight at present. There is less public funding available than there has been. With an ageing demographic the available funding is likely to decrease (due to a shrinking working population), the workforce available to provide care is also likely to decrease, and the number of individuals over the age of 85 who require care and support is likely to increase significantly. The current system is not sustainable. **Maintaining the status quo is not an option.**

### The role of this report

This research report accompanies a Policy Letter which will be taken to the States for debate in February 2016. The Policy Letter provides a summary of the strategic framework, asks for commitment to be made to the strategic direction, recommends an uprating in Social Security Contributions to take immediate action to address funding issues and requires the newly elected Policy & Resources Committee to establish a prioritised and resourced plan for implementing the recommendations put forward by the Working Party as set out in this research report.

This report: provides details of the areas that the Strategy covers; its relationship to other strategies; the issues considered by the Working Party to date; and the further work which needs to be undertaken in order to move the Strategy forward. It is intended that this report will act as a resource for the States, working in partnership with the private and third sectors, to build on the work and research undertaken so far. Making this report available publicly will assist future joint working by which the three sectors can combine their efforts and resources to provide better for the long-term health and social care needs of the two Island communities going forward.

The Report is informed by expert advice; internal research; and public engagement and consultation (as described in section 1 below). However, it is acknowledged that further research is required in a number of areas.

The Working Party accepts that **the scale of transformational change envisaged cannot and will not happen overnight**; pragmatically, services need to be developed incrementally. Some actions can be progressed faster than others. Many need further research, consultation and deliberation before implementation. In order to ensure progress is made, sufficient resources will need to be allocated to further research and the implementation of the proposed changes.

### The Strategy

The key elements of the Strategy are outlined in section 1 below. The Strategy recognises the need to balance improved outcomes for the individual with the effects on the community as a whole. The vision for the Strategy is: ***to have an adaptable and continuously improving care and support system that is fair, person-centred, enabling and sustainable.***

Changes need to be made to ensure that people experience a coordinated and joined-up response to their needs. They should be provided with clear information and offered support appropriate to their needs across a full range of community and residential care services. They should be included in decisions made about their care. Every effort should be made to prevent the avoidable increase of needs. Focusing on meeting people's needs and supporting people to prevent avoidable deterioration should reduce costs in the long-term.

### Core areas for change

The Working Party believes that in order to align provision with the strategic direction identified and outlined in section 1, significant changes need to be achieved in the following areas:

**A. *Developing the role of the States of Guernsey [Section 3]***

*The States of Guernsey should take a strategic role in developing a "care community" working in partnership with the private and third sectors. This will involve effective data gathering and analysis; appropriate data sharing; providing information to the public; regulation of care services; analysis and development of the relationship between different services in order to improve coordination; and effective linking with other key areas of strategic policy.*

**B. *Addressing unhelpful social attitudes [Section 5]***

*Attention must be given to addressing ageism, and ensuring disabled people and their carers are socially included. Community approaches to loneliness should be explored. It is important that care and support is enabling and supports people to live meaningful lives, and that care and support are not seen as simply doing things for people.*

**C. *Reconfiguring and developing services (in-house and through other providers) [Section 6]***

*Services need to be developed in all areas including care homes, supported living services and care in the community. However, areas for immediate priority action should include expanding support for informal carers (including short-break services); establishing a reablement service to help people to regain independence after being admitted to hospital; and establishing a proactive care coordination service where a single point of contact can case manage an individual's care, where they are receiving care from multiple providers, in*

*order to ensure that the approach is effectively joined-up and that individuals are aware of all of the services open to them.*

**D. *Reconfiguring the funding structure [Section 7]***

*The funding structure should be sustainable and should balance the mitigation of financial risk to the individual against the tax burden on the wider community. A three staged approach is suggested: firstly, increasing Social Security Contributions by at least 0.5%; secondly, by increasing the long-term care co-payment (in order to cover living and accommodation costs); and thirdly, to expand the scope of the Long-term Care Insurance Scheme to allow Long-term Care Benefit to be used to purchase domiciliary care at home and in supported housing options. This is likely to involve exploring whether further measures are required to make the system financially sustainable and the exploration of the possibility of introducing personal budgets.*

This report outlines in detail the initial actions that the Working Party believes need to be undertaken to move forward in each of these four areas.

## Section 1: Introduction and overview of the Strategy

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### 1.1 Introduction

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This research report presents the findings of the work carried out to develop a **Supported Living and Ageing Well Strategy**, also known as ‘**SLAWS**’. The Strategy is intended to review all care and support services<sup>1</sup> provided to individuals aged over the age of 18 years with enduring care and support needs<sup>2</sup>.

#### *What is care and support?*

For some, the term ‘long-term care’ has become synonymous with the care provided in private residential and nursing homes. However, the Strategy covers all forms of care and support provided or received in Guernsey and Alderney.

Whilst many people are able to manage their long-term conditions themselves without support, others may need help with transport, housework, paperwork, food preparation, personal care (e.g. bathing, eating or getting out of bed in the morning), may need support to go out, or may simply need someone to talk to. All of these are forms of long-term care and support.

Consequently, it is the requirement for care and support by an individual that defines long-term care, not the place or situation where that care and support is provided. Long-term care thus encompasses a wide range of formal services, as well as the care provided by unpaid family members and other informal helpers. It is distinguishable from acute care as it is provided to individuals with enduring needs, including chronic, disabling conditions or impairments, who need support on a permanent or ongoing intermittent basis.

Furthermore, because residential and nursing homes are populated predominantly by older persons, long-term care has become more commonly associated with services provided to older people. However, as already described in this report, persons of all ages can require long-term care or support and this Strategy is, therefore, focused on the needs of adults aged 18 years and over<sup>3</sup>. Whilst older adults may have physical conditions associated with ageing or dementia, 18-65 year old adults may have care and support needs associated with physical or

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<sup>1</sup> Whilst related to health care, this report focuses primarily on ‘social care’. This does not include medication, treatments, diagnosis, screening programmes, operations or specialist appointments. Social care is the care and support that a person needs to live on a day-to-day basis - this might be, for example, help getting out of bed, help with food preparation, help with washing or dressing, assistance with paper work, or attending appointments.

<sup>2</sup> This report purposely does not define ‘enduring care and support needs’, as it proposes a needs based/social approach and not a clinical definition. Individuals with care and support needs may include, but are not limited to, individuals with physical impairments, learning disabilities, enduring mental health conditions, autism, chronic illness, neurological conditions, and conditions associated with ageing.

<sup>3</sup> The Children and Young People’s Plan considers service requirements of Islanders aged less than 18 years.

learning disabilities, autism, mental health conditions, chronic illnesses, or through other causes.

The Strategy covers all areas of care and support, considering how best to support people who live at home and who are cared for by their family or friends; those who are cared for by community services delivered into their own homes; those who are cared for through supported living options, such as sheltered and extra care housing; together with those who live in residential and nursing homes or in a hospital-based setting, or in long-term off-Island placements.

#### *What is this report?*

The report has been prepared for the Policy Council by a political level Working Party that was established by the Social Policy Group in November 2013. It has been developed in order that the States of Guernsey, working with private and third sector providers<sup>4</sup>, can build on the work and research undertaken so far and combine their efforts and resources better to provide for the long-term health and social care needs of the community going forward.

A fundamental driver for the Strategy is that the Islands' populations are ageing and that our societies are changing. The good news is that as a population we are generally living longer and enjoying more healthy years in retirement. However, the changing demographic of the Islands' populations will mean that between now and 2065 there will be an increasing number of old and very old people in the Islands and fewer people of working age. As this will place heightened pressure on the funding of services at a time of increased demand, and at a time of a reduction in the number of people available to work, pay taxes and provide informal care<sup>5</sup>, this report also looks at ways to fund sustainably the provision of a full range of long-term care and support services in the future and to identify creative ways to mitigate against increasing long-term costs. In this respect, the report advocates the value of investing in preventative measures to help contain future escalating costs, wherever possible.

The Working Party has focused on reviewing existing services and identifying any gaps in provision. This has been achieved by carrying out an audit of existing services to understand better the number of individuals accessing care and support; the costs attached to different elements of the current system; and their present funding mechanisms. It has also engaged external assistance to help identify gaps in provision and has consulted widely within the Islands to understand where improvements can be made.

It has become apparent to the Working Party that whilst some services are available to support people living in the community, these services are relatively under-developed in a health and social care system that currently places a greater emphasis on a high intensity, bed-based, institutional provision of care. This bias needs to be rebalanced by improving the availability of care in the community, though all forms of care are likely to need to expand in coming years to cope with increasing demand.

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<sup>4</sup> The term 'third sector' includes charities, voluntary groups and non-governmental organisations, including some not-for-profit care providers.

<sup>5</sup> 'Informal care' refers to the unpaid care and support provided by family and friends.

A full **glossary of terms** used in this document and in the accompanying Policy Letter is included as **Appendix A**.

## 1.2 Why a Supported Living and Ageing Well Strategy?

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There has been sustained political interest in seeing a Strategy for Supported Living and Ageing Well presented to the States of Deliberation.

Originally intended to be an Older People's Strategy, the synergies between this and a separate piece of work that had commenced on adult supported living, led to the decision to combine the two into one strategy not just for older people, but for all adults who required some form of long-term care: hence it being renamed the **Supported Living and Ageing Well Strategy** – commonly known as 'SLAWS'.

The Supported Living and Ageing Well Strategy is significant:

- As a cross-departmental, **corporate level Strategy** intended to set a clear direction for the development of care and support services and funding across the Housing, Health and Social Services, Social Security and Treasury and Resources Departments. It is key to bringing together different perspectives on providing care and support and ensuring **coordination** going forward.
- As critical to the Islands' ability to **plan for long-term changes** which will, if no action is taken, undermine the sustainability of existing systems. The most significant of these being the Islands' ageing populations.
- To **recognise and address existing needs** which are not met by the current care and support system.

This section outlines some of the pressing long-term changes and existing needs which are drivers for the development of the Strategy.

The following drivers for change are considered in detail:

- (i) Demographic challenges;
- (ii) Changes in society; and
- (iii) The need to deliver more targeted and better co-ordinated services.

### 1.2.1 Demographic challenges

Like other advanced economies around the world, our populations are ageing. This is a combination of the fact that the 'baby-boomer' cohort<sup>6</sup>, the Bailiwick's largest ever generation with the most people, has recently or will shortly reach retirement age and the fact that all people are living longer lives.

It is good news that people are living longer lives than previous generations. However, this also means that a higher proportion of the population will be over retirement age. Older people are

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<sup>6</sup> Individuals born between the end of the Second World War and the mid-late 1960s.

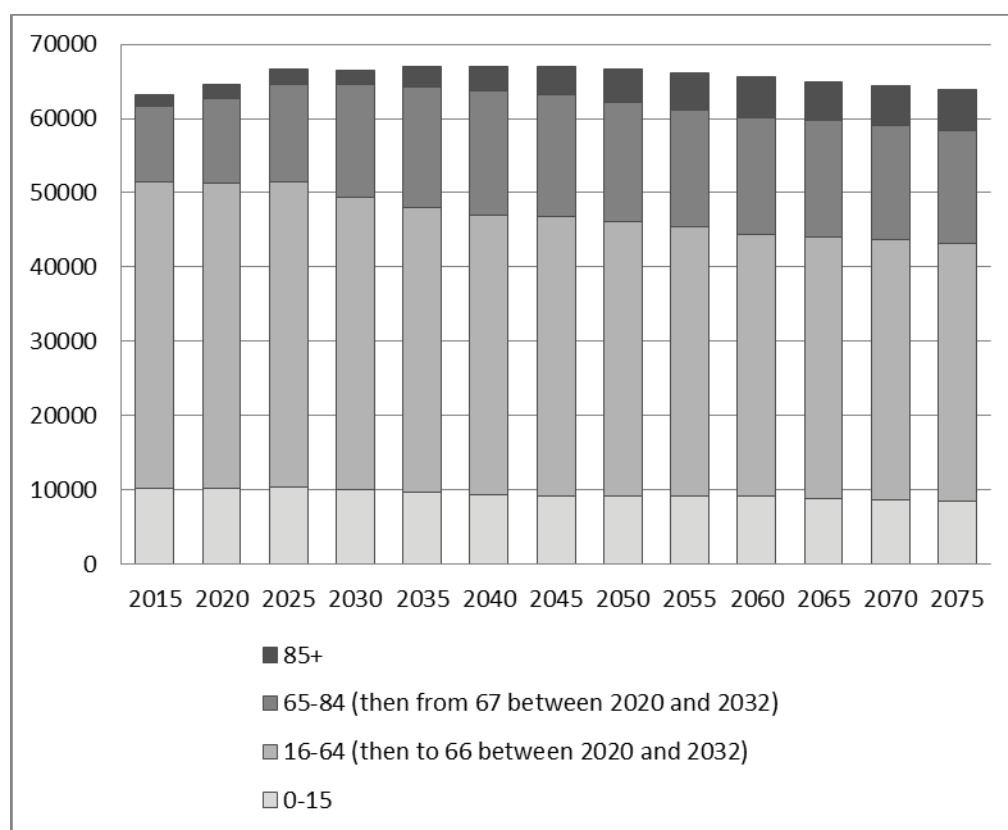


more likely to require health and social care services, and where they do require services are likely to have multiple pre-existing conditions (co-morbidities). This could, for example, include situations in which an older person has a fall and breaks a hip but already has diabetes, or where someone has a heart condition which requires treatment but also dementia. This combination of care needs can complicate and increase the cost of care and support provision. Due to increases in medical technology, younger adults with previous life-limiting conditions are also living longer into adulthood and old age with complex needs.

So there will be increased demand on services and a need for services to cope better with complex conditions. Simultaneously, there will be fewer people of working age to work in the care sector and pay taxes to fund services. This demographic change has, therefore, wide reaching implications for our community, our economy, and our government.

Of particular relevance to the development of the Strategy is the increasing proportion of ‘very old’ people in the population (the group most likely to have multiple long-term conditions), with the number of people over the age of 85 years in Guernsey expected to more than triple by 2050. This is shown in **figure 1A** below.

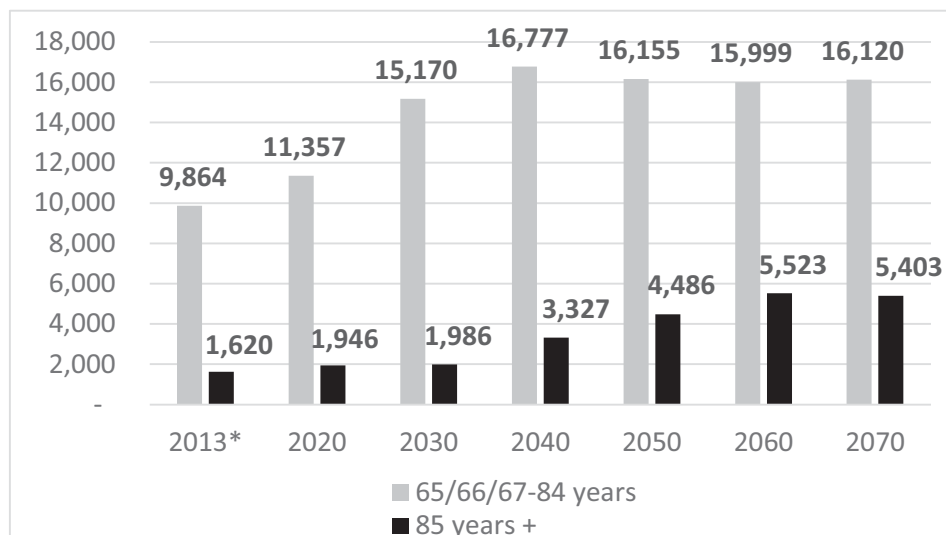
**Figure 1A: Projected population by age group for Guernsey<sup>7</sup>**



<sup>7</sup> This information is taken from ‘Guernsey Annual Electronic Census Report 31<sup>st</sup> March 2014’, which is available to download from [www.gov.gg/population](http://www.gov.gg/population). Figures are based on net immigration between 100 and 200 people per year. The projections take into account the planned retirement age increase to 67 but do not yet incorporate the planned retirement age increase to 70.

**Figure 1B** below looks more closely at projections of the number of people aged between retirement age and 84 years, and 85 years and over, until 2070. It shows that the number of Islanders aged over retirement age is expected to rise until in 2070: this will account for over 20,000 people, representing over 30% of the population. Meanwhile, the number of over 85s is set to more than triple, peaking in around 2060.

**Figure 1B: Population projections until 2070 of those Islanders aged over 65 years in Guernsey<sup>8</sup>:**



NB. The above uses projected population by age group, taken from the 2015 Rolling Electronic Census Report, in the scenario of plus 200 net migration<sup>9</sup>.

A further pressure will be a reduction in the number of people of working age to support the ageing population. The **dependency ratio** is expected to increase substantially; that is, the proportion of a population who are economically dependent - those who are eligible for retirement (over pensionable age) and those who are still in compulsory full-time education (children under compulsory school leaving age) - when compared to the number of people who are of working age (i.e. at present this is all those between the ages of 16 and 64 years).

As shown in **figure 1C** below, in 2014 the overall dependency ratio was 0.53, which means that for every 100 people of working age, there were 53 people of dependent age. The dependency ratio is expected to rise to between 0.82 and 0.89 by 2060 meaning that the burden on those who are working to pay for services will increase. The dependency ratio in

<sup>8</sup> The Guernsey Rolling Electronic Census Report uses population projections produced periodically by the UK Government Actuary's Department, primarily for the purpose of actuarial review of the Guernsey Insurance Fund for the Social Security Department. This information was updated in April 2014.

<sup>9</sup> More information about population projections and population projections by age band is available on page 19 of the 'Guernsey Rolling Electronic Census Report 31<sup>st</sup> March 2014'.

Alderney is significantly higher than the combined average for both Islands. In 2014 the ratio for Guernsey was 0.53 and for Alderney was 0.72<sup>10</sup>.

**Figure 1C: Projected changes to the dependency ratio in Guernsey's population between 2020 and 2070**

| <i>Year</i> | <i>Dependency ratio -<br/>in 100 net migration<br/>scenario</i> | <i>Dependency ratio -<br/>in 200 net migration<br/>scenario</i> |
|-------------|---|---|
| 2020        | 0.58  | 0.57  |
| 2030        | 0.70  | 0.68  |
| 2040        | 0.80  | 0.76  |
| 2050        | 0.83  | 0.77  |
| 2060        | 0.89  | 0.82  |
| 2070        | 0.87  | 0.82  |

NB. The above projections include the gradual change of the retirement age from 65 to 67 years between 2020 and 2032.

Whilst Guernsey's changing population profile – an increased number of older Islanders and less economically active Islanders - will put pressure on the availability of services and the funding of the Island's health and social care system, there are also a number of other factors which act as drivers for promoting changes to current services. These are outlined in 1.2.2 to 1.2.3 below.

### **1.2.2 Changes in society**

The Island's society is changing and people's expectations are also changing. In particular:

- **Family structures have changed and continue to change** - people are having fewer children and divorce rates have increased, which sometimes combine to break down family structures and support networks. The degree of responsibility for providing care to family members is changing and there may be fewer family members to care for older parents or relatives. Today, nuclear families are increasingly reliant on two incomes per family instead of one. This leaves less available time to provide care to extended family members.

Interviews from older people carried out as part of the 'What's Important to You?' consultation in 2008, revealed that a higher number of older Islanders felt isolated from traditional family and community support networks than the number of those who felt supported by family and community.

- **Family members are increasingly dispersed** - there may be an increasing number of older people in the Islands in the future who do not have family on-island.

<sup>10</sup> Annual Independent Fiscal Policy Review 2015, p. 32, available at: <http://www.gov.gg/annualindependentfiscalreview>.

- **Generational changes** – Many older Islanders who remained in Guernsey during the Occupation are relatively non-assertive about how their needs are met. They come from a generation of Islanders who are used to being self-sufficient and undemanding, where complaining about the quality or effectiveness of a service is almost unthinkable.

However, the ‘baby boomer’ generation (people born between 1946 and the mid-late 1960s), and subsequent generations of older people, are expecting more choice over what care and support they receive and how they receive it compared with previous generations. People are now active consumers rather than simply recipients of services and this increasingly extends to health and social care.

It is, therefore, not just the impact of an ageing population that presents an issue for developing an effective Supported Living and Ageing Well Strategy, but the values and attitudes that were forged during a period of great social change, mainly in the 1960s. This will require change in the types of services and how they are delivered.

**There are a range of technological and environmental changes.** On the plus side, changes in technology provide an opportunity to change what care and support is needed. These might include:

- **Development of medical interventions** – which can treat or prevent the development of conditions which are currently widespread. For example, if there were ground-breaking and readily available treatment for dementia, the way in which social care for people with dementia is planned would need to change.
- **Development of assistive technology** – technology and/or equipment which promotes greater independence by enabling people to perform tasks that they would otherwise be unable, or find difficult, to carry out for themselves. Such technology enables people to navigate disabling environments and helps to retain people living in their own homes by helping them with everyday tasks.
- **Development of telecare and telehealth** – technology which allows people to communicate with health professionals who are in different locations (telehealth), or allows for people to call for help and allows certain warning signs to be monitored remotely (telecare). (This is explored further in section 6).
- **Development of enabling environments** – design of buildings and public spaces to be more accessible to people with mobility problems or sensory impairments. (This is also explored further in section 6).

The Strategy provides an opportunity to consider these long-term changes and how to make our system adaptable to cope with challenges and take advantage of opportunities.

### **1.2.3 There is a need to deliver more targeted and better co-ordinated services**

As the needs of Guernsey and Alderney’s populations have changed, models for delivering care and support have not kept pace with these changes and are often not sufficiently coordinated or person-centred.

The findings of the research carried out by the Working Party, together with that carried out on its behalf by Melinda Phillips in 2014<sup>11</sup>, have led to the conclusion that services need to be targeted more effectively and require better co-ordination as part of an integrated system:

*Traditionally the system in Guernsey and most advanced economies has been based on hospital treatment of illnesses as they arise. If the illness persisted the patient would either stay in hospital or move into [institutional] long-term care. However, technology, better diets and healthier lifestyles have meant that we are living longer, often managing long-term conditions for several years...*

*All systems are struggling to shift the balance from hospitals and care homes to self-management in one's own home for as long as possible with the right support. This in turn requires services to be delivered differently so that they are focused on the person's needs and delivered in a co-ordinated way.*

*So, the overarching requirement of any system is to offer integrated person centred coordinated care and provide choices.*

Whilst there is a general need for development of the system to cope with multiple and complex conditions in a coordinated way, there are also concerns that, at present, individuals are not always best placed within existing services – either due to historical anachronisms, or lack of availability of the service which would most appropriately serve them. This can mean that placements do not meet the service user's needs or that placements are of a higher-intensity than they need to be. Unnecessarily high-intensity care placements can be both expensive and can lead people to lose confidence in their abilities to care for themselves. Examples can include:

- Working-age adults with disabilities being cared for in private care homes which cater mostly to older people.
- Individuals remaining in hospital due to lack of availability of placements in care homes or lack of availability of community services staff to support them as they move home.
- Individuals in care homes who have been admitted for historical reasons not related to their own care and support needs remaining in care (for example, individuals who have moved into a care home with a spouse due to the care needs of the spouse, who have then remained in a care home after the spouse has passed away).
- Individuals in off-island placements whom it may be possible to care for on-island.

In order to prevent inappropriate placements the whole system needs to be examined to identify where there is a lack of capacity in services, where there are service gaps, and where placement allocation is not working effectively.

As this is one of the primary reasons for developing the Strategy, the level of transformational changes required to bring about structural changes in the ways in which services are delivered is outlined in further detail in this report, particularly in sections 6 and 7.

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<sup>11</sup> See section 1.5 a).

### 1.3 The Working Party

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In order to address these challenges, in November 2013 it was agreed that the Strategy development should be led by the Policy Council, acting through its Social Policy Group (SPG). In turn the SPG agreed that a Working Party would be established, formed of political representatives of the Health and Social Services, Housing, Social Security and Treasury and Resources Departments, with a view to seeing the formulation of a Strategy through to completion. The then Chief Minister, Deputy Peter Harwood, was appointed as its Chair, and has continued in this role following his resignation as Chief Minister.

The political members of the Working Party have been as follows:

Deputy Peter Harwood, Chair  
 Deputy Hunter Adam, Treasury and Resources Department  
 Deputy Mark Dorey, HSSD (until September 2014)  
 Deputy Paul Luxon, HSSD (October-November 2014)  
 Deputy Michelle Le Clerc, HSSD (from December 2014)  
 Deputy Sandra James, Social Security Department  
 Deputy Dave Jones, Housing Department (until May 2014)  
 Deputy Paul Le Pelley, Housing Department (from May 2014)

The Terms of Reference of the SLAWS Working Party are provided in **Appendix B**.

The Working Party has been advised and supported by staff from the Policy Council, the Health and Social Services, Treasury and Resources, Social Security and Housing Departments.

The SLAWS Working Party has provided regular reports and updates on progress to the Policy Council's SPG over the last two years, with papers and action sheets being made available to all SPG Members and to the Members of each of the boards represented on the Working Party.

In addition, the Working Party has tested its thinking with a **Public Engagement Steering Group**, formed of representatives of Ageing Well in the Bailiwick<sup>12</sup>, the Guernsey Disability Alliance<sup>13</sup> and the States' Champion for Disabled People.

In addition to the above, the Working Party recognises the valuable input, via consultation and other means, of a wide range of health and social care professionals, service users and others who have contributed to the development of the Strategy, and would like to thank all of those involved for their contributions.

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<sup>12</sup> Ageing Well in the Bailiwick is a group brought together by the Guernsey Community Foundation which consists of representatives from organisations working with older people, from the private, voluntary and public sectors.

<sup>13</sup> The Guernsey Disability Alliance includes representatives from more than 30 local disability charities, plus individual disabled people, their families, and the professionals who support them.



## 1.4 The Strategic Framework

**Recommendation 1a): To endorse the strategic framework for the Supported Living and Ageing Well Strategy.**

The following Strategic Framework is intended to provide the core of the Strategy and the values and high-level outcomes that the Strategy is intended to achieve. All proposed workstreams should work towards the development of these outcomes. The vision and outcomes have been developed throughout the process. As a result of the feedback received from the public consultation (see 1.5 below) and to draw the Strategy in line with other social policy under development, the principles of the Strategy originally formulated by the Working Party (see appendix C) have subsequently been reformulated as outcomes.

The Strategy is a response to the challenges outlined in section 1.2 above. It recognises the pressing need to reconfigure services to cope with financial pressures associated with the ageing population, for social and generational changes, for the pressures on workforce, and for the need for the care system to adapt to cope with supporting an increasing number of people with multiple and complex long-term conditions.

**The purpose of the Strategy is as follows:**

*With regard to the care and support needs of adult (18+) Islanders to identify:*

- *What care and support services are needed?*
- *Who should provide them?*
- *How they should be funded?*

**The Strategy's vision is:**

*To have an adaptable and continuously improving care and support system that is fair, person-centred, enabling and sustainable.*

**Priority outcomes for individuals with care and support needs and their carers:**

1. **Person-centred:** *to have their care and support needs considered holistically and addressed by a comprehensive, multi-sector coordinated approach rather than through piecemeal service provision and support. Care and support provision should be sensitive to the individual's context, their existing social network and relationships, interests, and life goals.*
2. **Dignity, peace of mind and safety:** *care services should be safe, regulated, and high quality. Support and advice should be available to those who have concerns about their own safety, dignity and wellbeing, or that of someone they care about, together with appropriate safeguarding for all 'adults at risk'.*

3. **Informed and included in decision making:** *all adults should be supported to exercise as much self-determination as possible, and have opportunities to make informed choices. This can range from simple day-to-day choices about what to wear, to important life decisions about where to live and who to live with.*
4. **Reach health and wellbeing potential and prevent avoidable deterioration:** *all adults with care and support needs and their carers should be supported to achieve the highest possible standards of physical and mental health in their day to day lives.*

**Priority outcomes for the community:**

- I. **Financial sustainability and affordability of care and support in the medium to long term.**
- II. **Strategic, evidence-based and effective continuous development:** *service development will be evidence-based, effective, and respond to strategic pressures for change.*
- III. **Partnership working within and across the Islands:** *a partnership culture will be established whereby the public, private and third sectors, service users, and their carers can each contribute to service delivery developments; including sharing aggregated and personal data appropriately.*
- IV. **Inclusion of all people with care and support needs in community life:** *all individuals, no matter what age or disability, should be included in community life. Social, physical, psychological and financial barriers should be addressed where possible.*
- V. **The care sector should be a good place to work:** *care staff should be supported, respected and assisted in their career development.*

It is recognised that these outcomes are high-level and do not have specified measures or key performance indicators (KPIs) to monitor the success of the Strategy. The Working Party proposes that, as part of the next stage of the Strategy's development, KPIs be put in place to provide meaningful ways of measuring the success of the Strategy against these outcomes. Regular reporting on these will be an important part of the proposed new strategic planning role of the States, as outlined in section 3.

## 1.5 Research and consultation

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### a) Research

The Working Party has carried out detailed research into the wide range of long-term care and support services – in particular, within the public sector - to aid the development of the Strategy. Much time has been spent collecting and analysing data in order both to evaluate and understand current services and to inform future policy-making and service development. Some consideration has also been given to the way in which care and support systems in other jurisdictions are structured and the key debates and issues surrounding different key policy options.

In addition, the Policy Council engaged an external adviser, Melinda Phillips<sup>14</sup>, to identify changes that should be made to the current care system in Guernsey to provide better services to Islanders.

To discuss their experiences, Phillips talked to a number of people in Guernsey familiar with the health and social care system either as service users or as health and social care professionals. These included General Practitioners, social workers and care providers.

The research carried out by Phillips has provided additional perspective to the research conducted by the Working Party. Her report to the Working Party can be read at [www.gov.gg/slaws](http://www.gov.gg/slaws).

The Public Engagement Steering Group (comprising representatives of the Guernsey Disability Alliance, Ageing Well in the Bailiwick and the States' Champion for Disabled People) has also provided input for the Working Party to consider.

Where relevant, research undertaken for other strategies is drawn upon throughout the report.

### b) Consultation

#### i) SLAWS Public Consultation - June/July 2015

In June 2015, the Working Party issued a consultation document<sup>15</sup> outlining the background to the Strategy and invited comments, feedback and evidence to help guide its development.

The consultation document:

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<sup>14</sup> Phillips was selected to carry out this research based on her extensive background working across housing, health and social care and her wide understanding of how services need to work in a co-ordinated way to improve people's experiences. Previously the Chief Executive of Housing21, a housing, care and support provider, with prior knowledge of Guernsey through her past involvement in the development of Rosaire Court and Gardens, she also had experience of developing health and social care policy in the UK.

<sup>15</sup> The consultation document can be viewed at [www.gov.gg/slaws](http://www.gov.gg/slaws).

- provided an overview of existing care and support services in Guernsey;
- highlighted the challenges in delivering care and support services in the Bailiwick;
- focused on the delivery of services, the range of services provided, and the role of the public sector in service delivery;
- provided a summary of the range of issues under consideration by the SLAWS Working Party; and
- discussed and offered possibilities of the ways in which services could be funded.

Over 300 online survey and written responses were received to the consultation, which ended on 22<sup>nd</sup> July 2015.

A detailed summary of the findings of the public consultation document was published by the Working Party in 2015 and is available to download from [www.gov.gg/slaws](http://www.gov.gg/slaws).

The feedback received during the consultation has helped to inform the resultant Strategy and is referenced throughout this report and attached as appendix D.

**The Working Party would like to thank all those organisations and individuals who took the time to respond to the consultation and to provide evidence to support the Working Party's research and views about current provision, which has helped to set this agenda for change.**

## ii) Other relevant surveys

In addition to the above consultation specific to the Strategy, a number of public research projects and wide-reaching surveys have been undertaken by States' departments in recent years, which have also provided a wealth of information of relevance.

A Disability Needs Survey was carried out in 2012 to inform the Disability and Inclusion Strategy<sup>16</sup>; this provided information about the number of disabled people in the community, the challenges that they face, and their level of need. A consultation was also carried out in 2013 to advise the Personal Tax, Pensions and Benefits Review, which asked questions about the public's view of how public finances could cope with the pressures of the ageing population.

### *'What's Important to You?'*

Of particular interest are the findings of a survey of Islanders aged over 60 years that was carried out in 2008 for the development of the then Older People's Strategy.

The Survey – 'What's Important to You?' – was a major consultation event carried out in April 2008, via an Island-wide survey of all people aged 60 years and over. The aim of the consultation was to try to identify the top five most important issues for older

<sup>16</sup> See [www.gov.gg/disabilitystrategy](http://www.gov.gg/disabilitystrategy).

people in Guernsey. 13,644 surveys were distributed and there was a response rate of 28%. Responses were collected across the Island through GP surgeries, supermarkets, churches and community groups, as well as by HSSD and Housing Department staff.

The questions sought to take a snapshot of what older Islanders viewed as important. Islanders were asked to identify their top five priorities from the following list:

- Keeping in touch with my friends and maintaining my social life and contacts.
- My personal care and comfort. Making sure that I am still able to look after myself or that I can be cared for in my own home if I need help so that I am able to live comfortably and independently.
- Control over my daily life.
- Safe and secure neighbourhoods.
- Standard of housing. Making sure that the housing I live in is warm, dry and suitable for me to live in.
- Work and continuing to work.
- Support as a carer of my spouse/partner. Making sure that if I care for my spouse/partner I get the support I need to take breaks or receive help.
- Being in my own home. Being able to live in my own chosen environment, whether that is a room in a care home or a flat or a bungalow or a house. I can continue to live where I choose to live.
- Having a choice of housing available which will meet my needs if/as they change. This might be a flat or bungalow in a retirement community or a bungalow or flat where there is support or care (an emergency call system, help with shopping, help with bathing, etc.) provided if I need it.
- Being able to keep learning.
- Reliable and easy to use transport.
- Being able to get out and about easily to shop. Having easy access to shops and restaurants and public spaces.
- Being valued as a person and not feeling like a second class citizen just because I am older.
- Opportunities to keep fit and take exercise
- Taking part in outings, lunches and other social activities organised by voluntary groups like WRVS, Age Concern, Old Age Pensioners Association, etc.

Analysis of the results of this Survey showed that the top three priorities for older Islanders were:

- My personal care and comfort. Making sure that I am still able to look after myself or that I can be cared for in my own home if I need help so that I am able to live comfortably and independently.
- Being in my own home. Being able to live in my own chosen environment, whether that is a room in a care home or a flat or a bungalow or a house. I can continue to live where I choose to live.
- Control over my daily life.

Also identified as important were:

- Keeping in touch with my friends and maintaining my social life and contacts.
- Support as a carer of my spouse/partner. Making sure that if I care for my spouse/partner I get the support I need to take breaks or receive help.
- Having a choice of housing available which will meet my needs if/as they change. This might be a flat or bungalow in a retirement community or a bungalow or flat where there is support or care (an emergency call system, help with shopping, help with bathing, etc.) provided if I need it.
- Being valued as a person and not feeling like a second class citizen just because I am older.



## Section 2: Existing services and strategic context

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### 2.1 Strategic context - How does the development of the SLAWS link to existing States policy?

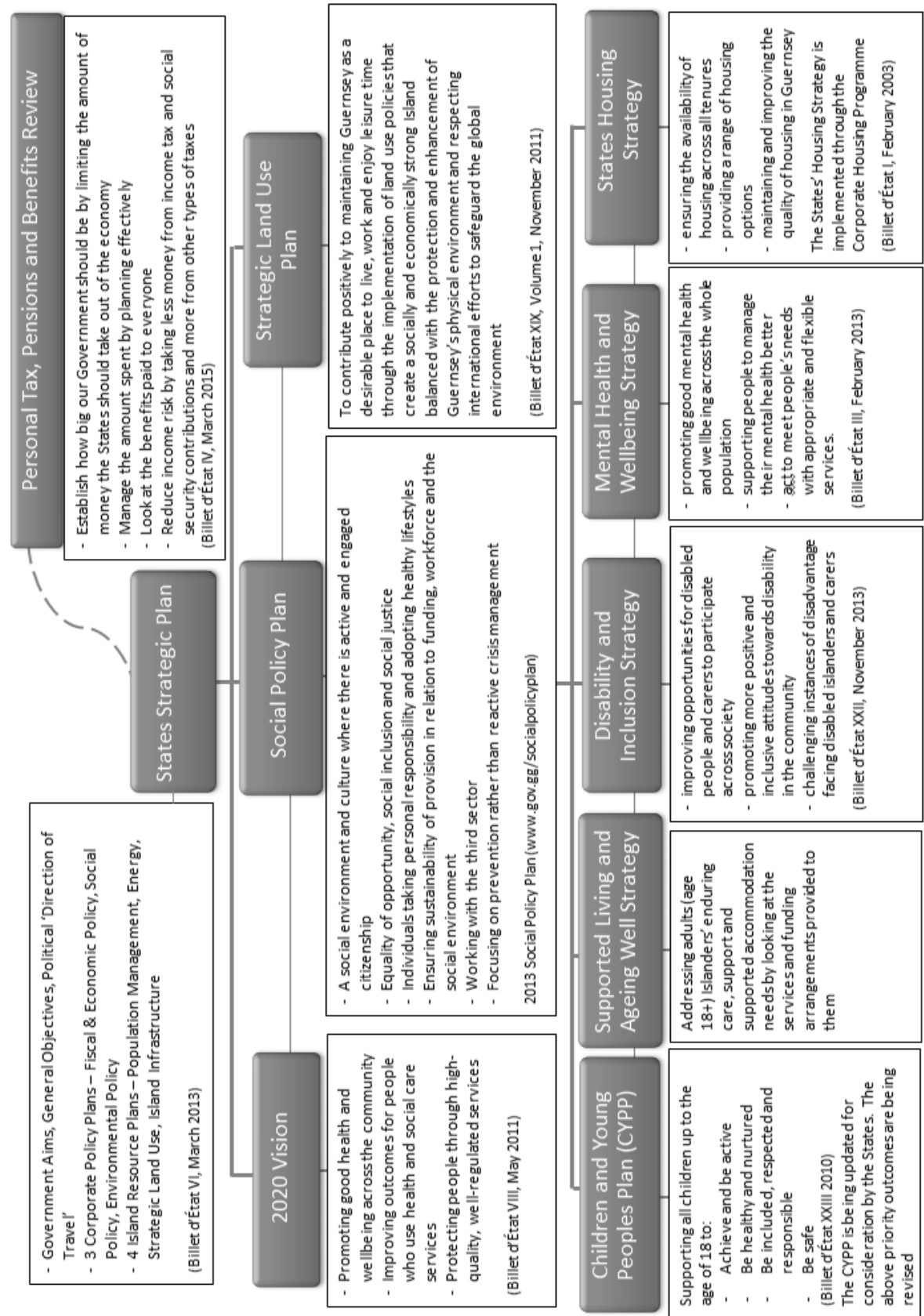
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This section considers the links between this Strategy and other areas of States' policy. It also describes:

- The States Strategic Plan and the Social Policy Plan;
- The Strategic Land Use Plan and the Island Development Plan;
- The States Housing Strategy;
- Health and Social Services Department's '2020 Vision' for the future of health and social care
- The Disability and Inclusion Strategy;
- The Mental Health and Wellbeing Strategy;
- The Children and Young People's Plan; and
- Planning a Sustainable Future - the Personal Tax, Pensions and Benefits Review.

**Figure 2A** below aims to map all of the relevant social policy initiatives and their interrelationships.

Figure 2A: Mapping of the interrelated strategies and relationship to the SLAWS



### ○ The States Strategic Plan and the Social Policy Plan

The **States Strategic Plan (SSP)** is the long-term planning mechanism to enable the States to decide what they want to achieve over the medium- to long-term and how they will manage or influence the use of Island resources to pursue those objectives. The latest version of the States Strategic Plan was considered and approved by the States in March 2013.

Although its name suggests that it is a single document it is in fact a ‘family’ or suite of inter-related plans, which includes Island Resource Plans for Population Management, Energy, Strategic Land Use and Island Infrastructure, together with three Corporate Resource Plans: the Fiscal and Economic Policy Plan; the Social Policy Plan; and the Environmental Policy Plan.

The most relevant of these plans to the development of this Strategy is the **Social Policy Plan**. The development of the Supported Living and Ageing Well Strategy was assigned as a ‘high priority’ in the Social Policy Plan in March 2013.

The purpose of the Social Policy Plan is to assist the States to develop and deliver services for people to meet their needs for welfare and wellbeing<sup>17</sup>. The areas covered by the Plan include health; social care; benefits; housing; employment; equality; education and security. The cost of providing government services in these areas takes up the largest proportion of the States’ Budget.

By adopting the Social Policy Plan, the States has agreed the following aims and objectives, all of which are of relevance to the SLAWS.

The Social Policy Plan General Objectives aim to achieve:

- A social environment and culture where there is active and engaged citizenship;
- Equality of opportunity, social inclusion and social justice; and
- Individuals taking personal responsibility and adopting healthy lifestyles.

In addition to the General Objectives, there are three themes that run through all work on the Social Policy Plan, which are:

- Ensuring sustainability of provision in relation to funding, workforce and the social environment;
- Working with the third sector;
- Focusing on prevention rather than reactive crisis management.

The Social Policy Plan acknowledged that there are many social policy challenges for government to overcome in achieving medium- to long-term objectives. The March 2013 report focused on four key issues - many of which are relevant to this Strategy - in particular:

- Shifting to preventative measures
- Availability of funding
- The ageing population

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<sup>17</sup> 2013 Social Policy Plan ([www.gov.gg/socialpolicyplan](http://www.gov.gg/socialpolicyplan)).

- Working better with the third sector

The Strategy has been developed in accordance with the Social Policy Plan objectives and themes.

In addition, the Working Party's recommendations, particularly those in relation to developing a sustainable model for funding long-term care, have had regard to the Fiscal and Economic Policy Plan (see section 7 for more information).

- **Strategic Land Use Plan and the Island Development Plan**

The **Strategic Land Use Plan (SLUP)**<sup>18</sup> is one of four Island Resource Plans which describe the ways in which the States proposes to manage or influence the use of Island Resources to support the overall Aims and Objectives of the States Strategic Plan. In each case, this involves considering how resources can best be used to support the Fiscal and Economic, Social, and Environmental Policy Plans and the States departmental Policy Plans.

The SLUP sets out a 20-year agenda for land use planning in Guernsey and has been used by the Environment Department to guide the preparation of the draft **Island Development Plan**<sup>19</sup>.

The SLUP, and the way in which the policy objectives of the SLUP are translated through the Island Development Plan, are relevant to the SLAWS in respect of ensuring that there are sufficient opportunities to provide a wide range of supported living options to meet the specific gaps in supported housing provision identified by this Strategy.

The draft Island Development Plan (sections 19.9.14 to 19.9.18) also sets out planning policies that incorporate specific design principles to improve the long-term suitability of all new build housing, by proposing that new build accommodation should be built to 'Lifetime Homes'<sup>20</sup> standards. Furthermore, proposals to alter or extend existing buildings to facilitate the provision of Lifetime Homes will be supported provided that they accord with the other relevant policies of the Island Development Plan, which will help to support those with long-term care and support needs who remain living at home.

Further consideration is given to the need to develop the range of supported living options in section 6 of this research report, which focuses on the need for appropriate forms of accommodation to help support people to remain living independently.

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<sup>18</sup> 'The Strategic Land Use Plan' - Billet d'État XIX 2011.

<sup>19</sup> The draft Island Development Plan was published in February 2015 and is available to view at [www.gov.gg](http://www.gov.gg).

<sup>20</sup> 'Lifetime Homes' are ordinary homes designed to incorporate design criteria from the outset that can be universally applied to new homes at minimal cost. In the Guernsey context this relates particularly to the need to incorporate design features in all new development, or to design development so that there is the potential to easily adapt it in the future, which can address the requirements of disabled residents or support the changing needs of occupants as they age (taken from the draft Island Development Plan, paragraph 19.9.15).

### ○ **States Housing Strategy**

The **States Housing Strategy**<sup>21</sup> was approved by the States in 2003<sup>22</sup> and sets out a set of strategic objectives, the fulfilment of which is intended through the Corporate Housing Programme (CHP), a practical framework for implementing the States Housing Strategy through coordinated action by States' departments, non-governmental organisations, voluntary groups and the third sector. The States Housing Strategy is part of the Social Policy Plan and aims to support the delivery of its General Objective and themes.

With particular reference to the development of the SLAWS, the States Housing Strategy includes the following aim:

*“To enable the provision of supported accommodation for persons with special needs including accommodation for older persons, young people, people with a learning disability, persons with a mental illness, ex-offenders etc.”*

### ○ **Health and Social Services Department's '2020 Vision'**

The HSSD's '2020 Vision' was debated and approved by the States in May 2011 and sets out a framework for future development of the health and social care system in Guernsey and Alderney. In approving this report, the States agreed that there should be three core elements to the work of the department:

- **Promoting** good health and wellbeing across the community;
- **Improving** outcomes for people who use health and social care services; and
- **Protecting** people through high quality, well-regulated services.

The SLAWS is a key strategy in helping to deliver HSSD's '2020 Vision' and in translating the above three core elements to the work of HSSD into practice. Indeed, this research report will show how the above three elements run throughout the Strategy.

One of the key elements in the '2020 Vision' report was to ensure that more appropriate management information was available for all parts of the system, both in terms of cost and quality, and that these measures were monitored on an ongoing basis. This is of particular relevance to SLAWS, as described further in section 3.

The '2020 Vision' also touched upon the need for services to be better developed at times of transition such as moving from child to adult services, an issue that is equally important to the Children and Young People's Plan and to this Strategy.

Also, as already described in the introduction to this report, developing better joint working arrangements with the third sector is a key element of this Strategy, an issue that was also highlighted in HSSD's '2020 Vision'.

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<sup>21</sup> The latest report to the States on the CHP entitled '*Corporate Housing Programme - Progress against the 2009 Action Plans*' was debated and approved by the States in May 2010 (Billet d'État XI 2010) .

<sup>22</sup> States Advisory and Finance Committee and the States Housing Authority 'The Development of a Housing Strategy and Corporate Housing Programme' – Billet d'État II, February 2003.

The '2020 Vision' also outlined the need for the health and social care system in the Islands to promote self-care and independence as part of a social care and prevention model as opposed to a health care model, which is more heavily focused on responding to the symptoms of illness rather than preventing their causes. As will be further described in this report, this Strategy – in particular section 6 – looks closely at specific areas of service delivery, and opportunities to work with third sector organisations, to ensure that resources are dedicated towards preventing health issues, where this is possible, as a means of improving individuals' health and wellbeing and reducing the long-term costs associated with long-term care.

#### ○ **The Disability and Inclusion Strategy**

In November 2013, the States considered and approved the **Disability and Inclusion Strategy**<sup>23</sup>. The Strategy aims to improve the quality of life of disabled Islanders and carers so that they can be actively engaged socially, economically and culturally, and that there are improved attitudes towards disabled people.

The Disability and Inclusion Strategy aims to do this by:

- **Improving** opportunities for disabled people and carers to participate across society;
- **Promoting** more positive and inclusive attitudes towards disability in the community; and
- **Challenging** instances of disadvantage facing disabled islanders and carers.

The initial focus is on providing information and education, backed by legislation and action.

Further information arising from the Disability Needs Survey carried out in November 2012 is outlined below, which describes the prevalence of enduring care and support needs among the population.

There are clear links between the aims of the Disability and Inclusion Strategy and the outcomes of this Strategy. The Disability and Inclusion Strategy specifically left the majority of service related issues to be addressed via the Supported Living and Ageing Well Strategy. In fact, both strategies are intended to be mutually reinforcing, with outcomes of the Disability Strategy helping to move forward elements of the SLAWS, and vice-versa. These strategic overlaps are signposted in the implementation plan included in the accompanying Policy Letter and are shown in **figure 2A** above; they are also referenced throughout this document, where appropriate.

An update report on the Disability and Inclusion Strategy was considered by the States in November 2015<sup>24</sup>. This Policy Letter provided an update on that Strategy's workstreams, including valuable work being taken forward to develop an information resource for disabled Islanders and their families and to develop condition-specific frameworks that address the needs of individuals with autism, communication difficulties, dementia, and learning

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<sup>23</sup> Policy Council – '*Disability and Inclusion Strategy*', Billet d'État XXII 2013.

<sup>24</sup> Policy Council – '*Update on the Disability and Inclusion Strategy*', Billet d'État XX 2015.



difficulties. These areas of work are of particular interest for the SLAWS, as highlighted in more detail in section 6.

- **Mental Health and Wellbeing Strategy**

In February 2013, the States of Deliberation approved a report from the Health and Social Services Department outlining a Mental Health and Wellbeing Strategy<sup>25</sup>. The Strategy is intended to promote mental health and wellbeing across the community, support vulnerable people, and ensure that appropriate and effective treatment is provided for those who need it.

The Strategy outlines the benefits of positive mental health and wellbeing and the influence this has across a wide range of domains, ranging from healthier lifestyles and better physical health to higher educational attainment, better relationships, greater social cohesion and improved quality of life.

Consideration of the report on the Mental Health and Wellbeing Strategy in 2013 was followed by consideration of a report by HSSD on the development of modern mental health facilities to replace the Castel Hospital, the Mental Health (Bailiwick of Guernsey) Law, 2010, which came into force in April 2013, and the priority given to the need to improve Islanders' health and wellbeing in HSSD's '2020 Vision'.

In common with the SLAWS, the Mental Health and Wellbeing Strategy requires the engagement of the whole community: adults and children; service users and service providers; the States; the third Sector; and the business community. The Mental Health and Wellbeing Strategy provides a framework within which it is intended that all areas of the Island community can begin to work together towards better mental wellbeing.

There are also important links between the Mental Health and Wellbeing Strategy and the SLAWS, which are identified throughout this report.

- **Children and Young People's Plan**

Running in parallel to the formulation of the SLAWS has been the development of a new Children and Young People's Plan (CYPP).

The first CYPP came into effect in 2011 and was extended for a further three years in December 2013. At the time of writing, it is anticipated that the Children and Young People's Plan 2016-2022 will be presented to the States in the same Billet d'État as the SLAWS Policy Letter.

The objective of the CYPP is to put in place a holistic and co-ordinated strategy for all children's services in Guernsey. This will enable the States of Guernsey, and its policy and delivery partners in the third sector, to prioritise how resources should be used, and will bring together all the organisations working with young people in schools and in the community, enabling them to work to a common agreed strategy.

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<sup>25</sup> Health and Social Services Department – '*Mental Health and Wellbeing Strategy*', Billet d'État III 2013.

Although the links between the SLAWS and the CYPP are less apparent than in other areas, the feedback received during the consultation processes on both strategies has highlighted the need to focus on the **transition** between child and adult services. Good knowledge of the needs of young people with enduring care and support needs can also help to plan future adult services so as to ensure that those needs can be met when the young people make that transition.

In addition, it is important to acknowledge that whatever can be done to assist Islanders to lead healthy, active and safe lives as children and young people will pay dividends in later life; in particular it will reduce the number of people requiring long-term care through poor lifestyle choices. Healthy eating, exercise and not smoking are all habits that can be established in younger years and carried through into adulthood.

- **The 2015 Personal Tax, Pensions and Benefits Review**

In March and April 2015, the States debated a report from the Treasury and Resources and Social Security Departments entitled 'Planning a Sustainable Future – The Personal Tax, Pensions and Benefits Review'<sup>26</sup>.

This States Report referenced the work being carried out to develop the SLAWS; in particular referring to the need to find a sustainable funding model for funding long-term care and to be mindful of the need to control government spending and the overall limits imposed by the Fiscal Framework.

The relevance of the 2015 Personal Tax, Pensions and Benefits Review is described in detail in section 7 of this report, in order to set the context for the Working Party's recommendations on strategic funding issues.

## 2.2 Existing services and needs

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The Working Party has carried out extensive research in order to determine the existing range of long-term care and support services provided in the Islands.

This section, therefore, looks closely at the existing need within the community and the complex range of care and support services that are delivered in Guernsey by the public, private and third sectors. Details are also provided of the key benefits and financial assistance provided by the Social Security Department to: people with disabilities; people in receipt of long-term care; and to those caring for someone who requires care and/or support.

This section will show that there is a wide range of assistance available in a range of settings.

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<sup>26</sup> Treasury and Resources and Social Security Departments – '*Planning a Sustainable Future*' – *The Personal Tax, Pensions and Benefits Review* - Billet d'État IV. See paragraphs 5.2.48 to 5.2.48 and recommendations 17 and 18.

### 2.2.1 Needs within our community

This section describes the Working Party's research to understand better the prevalence of needs within the Islands.

Whilst the Working Party has generally found it difficult to find sources of suitable data which indicate the number of people in our community with long-term care and support needs, it has drawn together the information that is available to begin to put into context the number of Islanders who might currently be in receipt of services or benefits associated with long-term care.

#### i) Disability Needs Survey

The Disability Needs Survey was carried out to inform the development of the Disability and Inclusion Strategy in 2012. It estimated that around 4,000<sup>27</sup> people's day-to-day lives were significantly affected by a long-term condition<sup>28</sup>: an estimated 6% of the population.

People whose day-to-day lives are significantly affected are part of an estimated total of just under 14,000 people (21% of the population) in Guernsey and Alderney with a long-term condition that affects their day-to-day life. Some people will manage their conditions themselves without support; others may need regular or occasional help with transport, housework, paperwork, food preparation, personal care (e.g. bathing, eating, getting out of bed in the morning) or may need support to go out or someone to talk to. For some people changes can be made to their environment which reduces the support that they need – for example, for someone who owns a two storey house and develops a need to be in a wheelchair, adapted housing might enable the person to live independently.

#### ii) 2011 Housing Needs Survey

The 2011 Guernsey Housing Needs Survey asked how many individuals reported having a long-term health issue. 5,675 people living in Guernsey were reported as having long-term health problems. It was reported that:

*“Of the 5,675 people who experienced long term health problems... 668 are in need of help with personal care e.g. bathing, dressing, toileting, eating etc. This accounts for just over 1% of the entire population of Guernsey. Of those who do require help with personal care only 34 are in need of a professional overnight carer, which accounts for only 0.1% of the population of Guernsey.”*

The questions which were asked in the Housing Needs Survey were framed differently to the questions in the Disability Needs Survey. A comparison of the two is made in Appendix 4 of the Disability Needs Survey<sup>29</sup>.

<sup>27</sup> This includes some individuals under the age of 16 years but it is thought that the number does not exceed 500 people.

<sup>28</sup> BMG (2012) Disability Needs Survey: Review of prevalence across Guernsey and Alderney. Available at <http://www.gov.gg/disabilitystrategy>.

<sup>29</sup> Available at: <http://www.gov.gg/disabilitystrategy>.

### iii) Needs Assessment Panel

The following Needs Assessment Panel<sup>30</sup> certificates were issued in 2014 for care homes (see section 2.2.3 below). This gives an indication of the need for bed-based high intensity care arising over the year, but does not give us a clear view of the level of need in the community. There are some individuals who have a high enough level of need to be cared for in a care home or hospital setting but who are cared for by their families in their own homes.

|   | Total certificates issued in 2014 |
|---|-----------------------------------|
| Hospital Nursing Care                           | 19                                |
| Nursing Care Home                               | 163                               |
| Residential Care Home                           | 113                               |
| Residential Elderly Mental Infirmity (EMI) Care | 47                                |

### iv) How many people are in receipt of States-funded services?

Whilst we cannot place a precise figure on the number of people supported, since some people use multiple services and there is a risk of double counting, we know that the formal care system supports approximately **2,000 adults**<sup>31</sup> at any one time in Guernsey and Alderney (about 3% of the total populations). This includes long-term care in States-provided residential settings in Guernsey and Alderney; people in receipt of Long-term Care Benefit in private residential and nursing homes; the number of people receiving care in extra care housing; complex off-Island placements; and community care services. In addition, many other people are cared for exclusively by their friends and family.

It has been difficult to calculate with utmost certainty the number of people that receive services because of the overlap between services and their users, as an individual may access more than one service which keeps its own data. Therefore, without cross-checking personal information between departments or service areas, which has not been possible, there is a chance that some service users are double-counted, although this has been avoided where possible. (The issue of effective data management across services is considered in section 3).

**For strategic planning purposes it would be helpful to have a standardised, regular, population wide view of care needs in the community.** This is discussed further in section 3 below.

## 2.2.2 The Care Continuum

<sup>30</sup> The Needs Assessment Panel is a body of professionals convened by HSSD to make decisions on where an individual's needs will most appropriately be met. A certificate confirming the level of need is required from the panel to access most forms of bed-based care. See section 2.2.3 below.

<sup>31</sup> This is the best available estimate. There are complications in identifying a total figure because, particularly for community services, people may claim benefits from Social Security and use several services from HSSD and it is not always possible to identify where one person is using multiple services to avoid double-counting. Development of data systems is something which needs to be addressed as part of the Strategy.

Existing services range from those supporting people with low needs who mostly take care of themselves, to people with complex or challenging needs who cannot be cared for in Guernsey and are offered specialist residential placements off-Island. As people's needs change and develop they may move along the continuum and transition into and out of different services. In order for this range of services to be experienced as a 'continuum', the Strategy has focussed on ensuring coordination and identifying gaps in provision and, importantly, that services work together, centred upon the person with care needs.

Across the care continuum there are some services which cater to specific levels of need (e.g. off-Island placements are only for people with very complex needs); while other services provide for a wide range of need levels (e.g. community services) (see **figure 2B**).

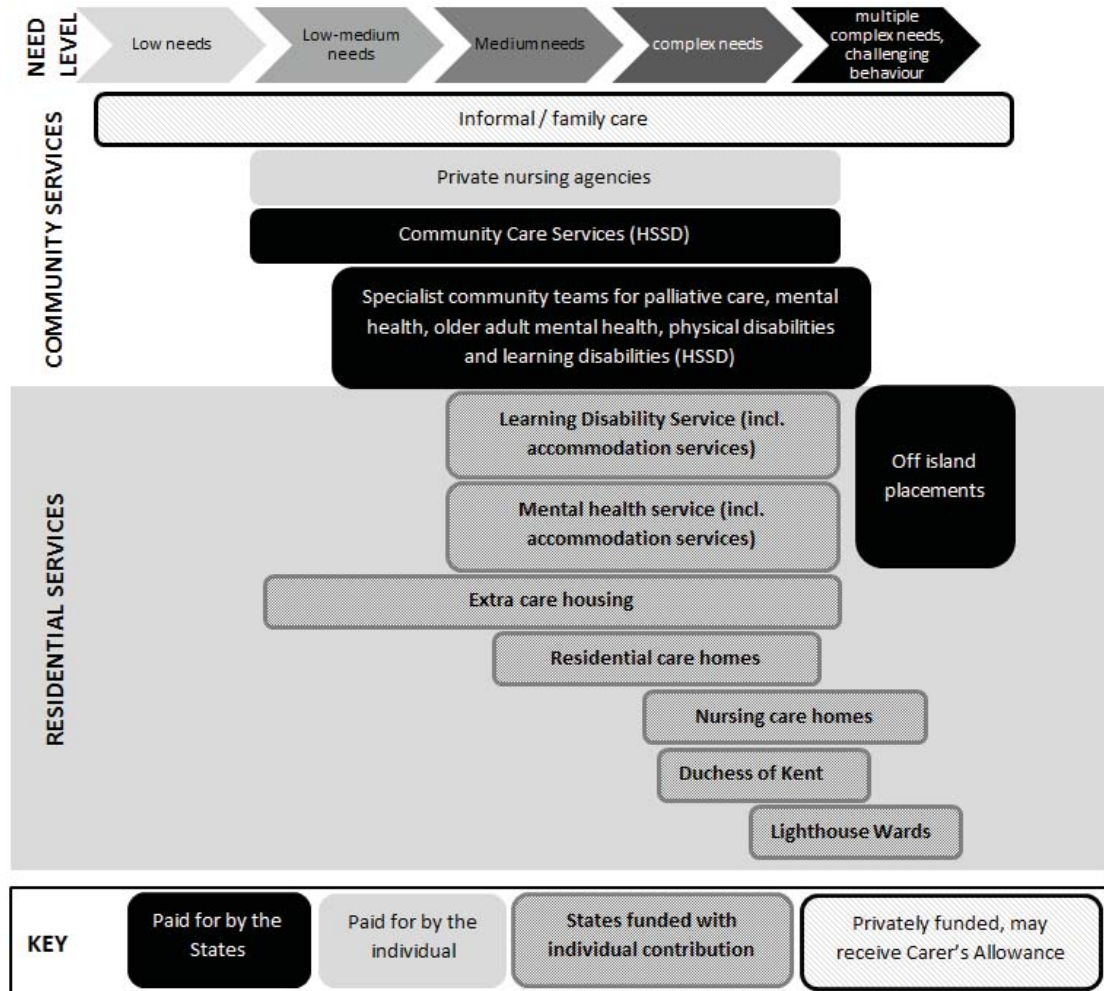
It is of strategic importance to ensure that people do not move up the care continuum faster than they need to, which would increase costs faster than necessary. This can be achieved, as will be outlined in section 6, by adopting **preventative services** and ensuring that people receive services that are **appropriate to their needs**, are **suitably coordinated** and can be **tailored to the individual**, all of which can help to ensure that costs are managed in an effective way. Furthermore, adopting a person-centred approach, rather than 'a one size fits all' model does not only help to mitigate against unnecessary expenditure, but also ensures that services are delivered to meet an individual's changing needs and those of their family and friends who may be involved in caring for them.<sup>32</sup>

As shown by the mapping exercise which follows, there is already in place a range of accommodation and housing support services across the care continuum to help individuals with care and/or support needs to maintain their independence (though some of these services may not always have the required capacity to meet demand) and a significant amount of funding from a range of sources is already invested to deliver these services in the Islands. However, whilst services are available to meet the full range of needs, research has shown that there is a requirement for more or better services at some levels and, in many cases, for services to be reconfigured and integrated in a more effective way to meet Islanders' needs. **This is at the heart of this Strategy.**

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<sup>32</sup> In financial terms, support for lower needs, generally speaking, tends to be less costly than providing for higher dependency needs. However, as highlighted in Section 7, depending on the level of weekly need, supporting choices which promote independence, particularly at higher levels, can sometimes be more costly.

Figure 2B: The concept of the 'care continuum' and details of service provision in each area of the care continuum in Guernsey.



### 2.2.3 Mapping existing services

#### a) Services delivered by the Public Sector

A detailed mapping exercise to establish the full range of services provided by the public sector; their number of service users; and the comparative present cost was completed in 2014/early 2015, in an effort to understand better the extent and reach of the services brought into the realm of the SLAWS.

This includes a number of social welfare and insurance benefits that are paid to individuals to enable them either to 'purchase' long-term care services, or (subject to means-testing) to enable them to meet their ongoing accommodation and living costs.

In an effort to summarise the scale of existing services, the following conclusions have been drawn from the mapping of public sector services<sup>33</sup>:

In 2014:

- (i) There were approximately **2,000 individuals** in receipt of care or support from the public sector to meet their needs;
- (ii) The cost to the States of providing these services was **in excess of £50 million**.

This includes the cost to the Long-term Care Insurance Scheme of subsidising residential and nursing care beds, but excludes any additional contributions by way of a 'top up'<sup>34</sup> made by individuals towards the cost of their care.

It also includes direct benefits payable to individuals and their carers but excludes the value of other financial benefits paid for by the Social Security Department. For example, it excludes Supplementary Benefit, which is available (subject to means-testing) across the population to meet individuals' day-to-day living expenses and/or accommodation costs.

Whilst this section of the report aims to summarise the services provided, section 6 builds on this research to make recommendations to improve service delivery in some areas; address gaps in services; and transform the ways in which services are coordinated.

**Figure 2C** is an organisational chart which summarises the different services delivered by the States of Guernsey to adults who require care and/or support<sup>35</sup>. This shows that the system is extensive and complex with many relationships between different services, which are often poorly understood.

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<sup>33</sup> The desire to report to the States this political term has not permitted a similar analysis of services provided in the private and third sectors. However, with the exception of residential and nursing homes, private and third sector service provision is somewhat limited and/or under-developed. For example, there are very few domiciliary care providers outside of the States, and these tend to be accessed only by those individuals with the financial means to do so.

<sup>34</sup> See Section 7.2 for an explanation of this term.

<sup>35</sup> It should be noted that whilst all of the services shown are in operation, staffing and other resource limitations may restrict the availability and effectiveness of some services at certain times.



Figure 2C: An overview of key public sector services for adults with long-term care needs

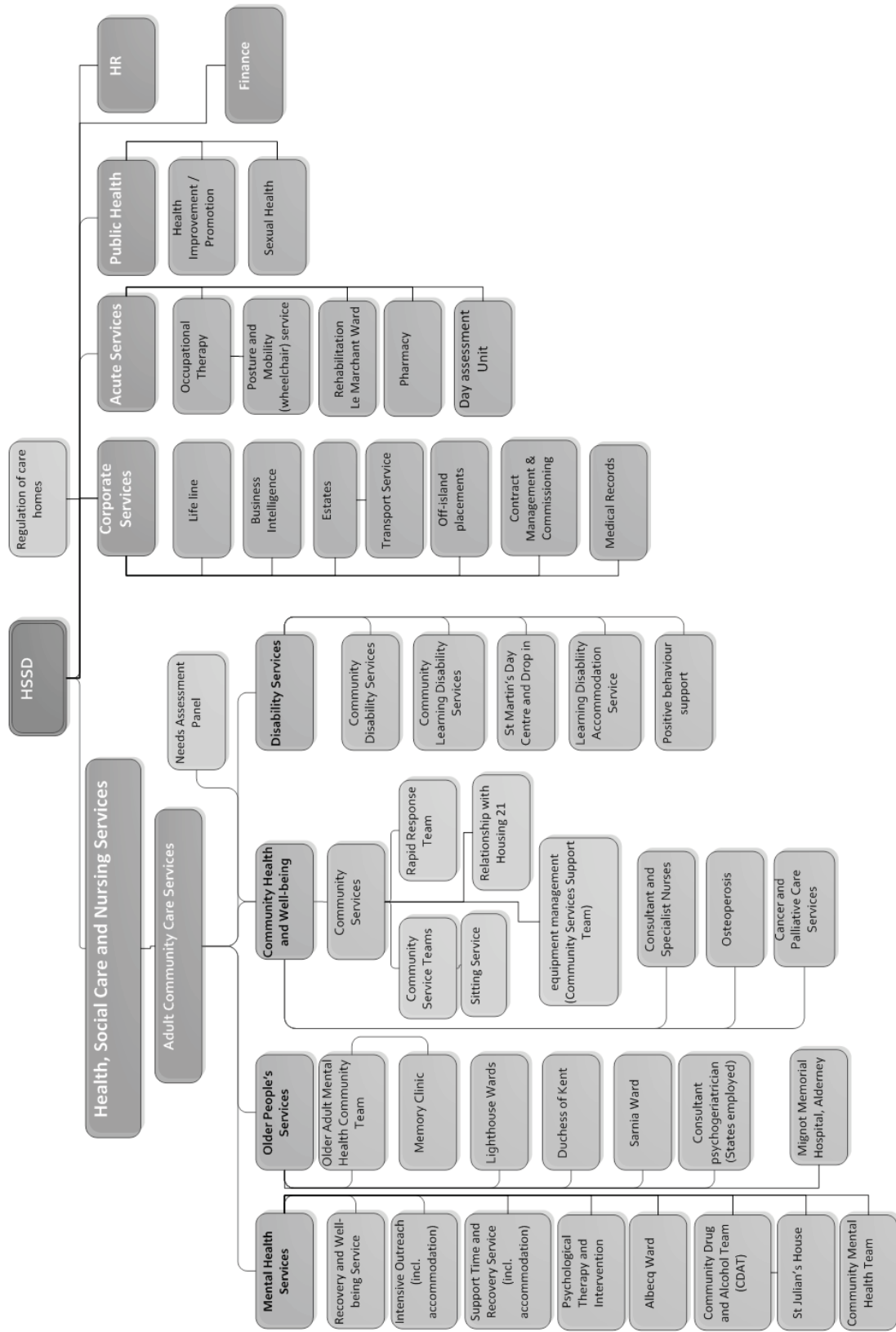
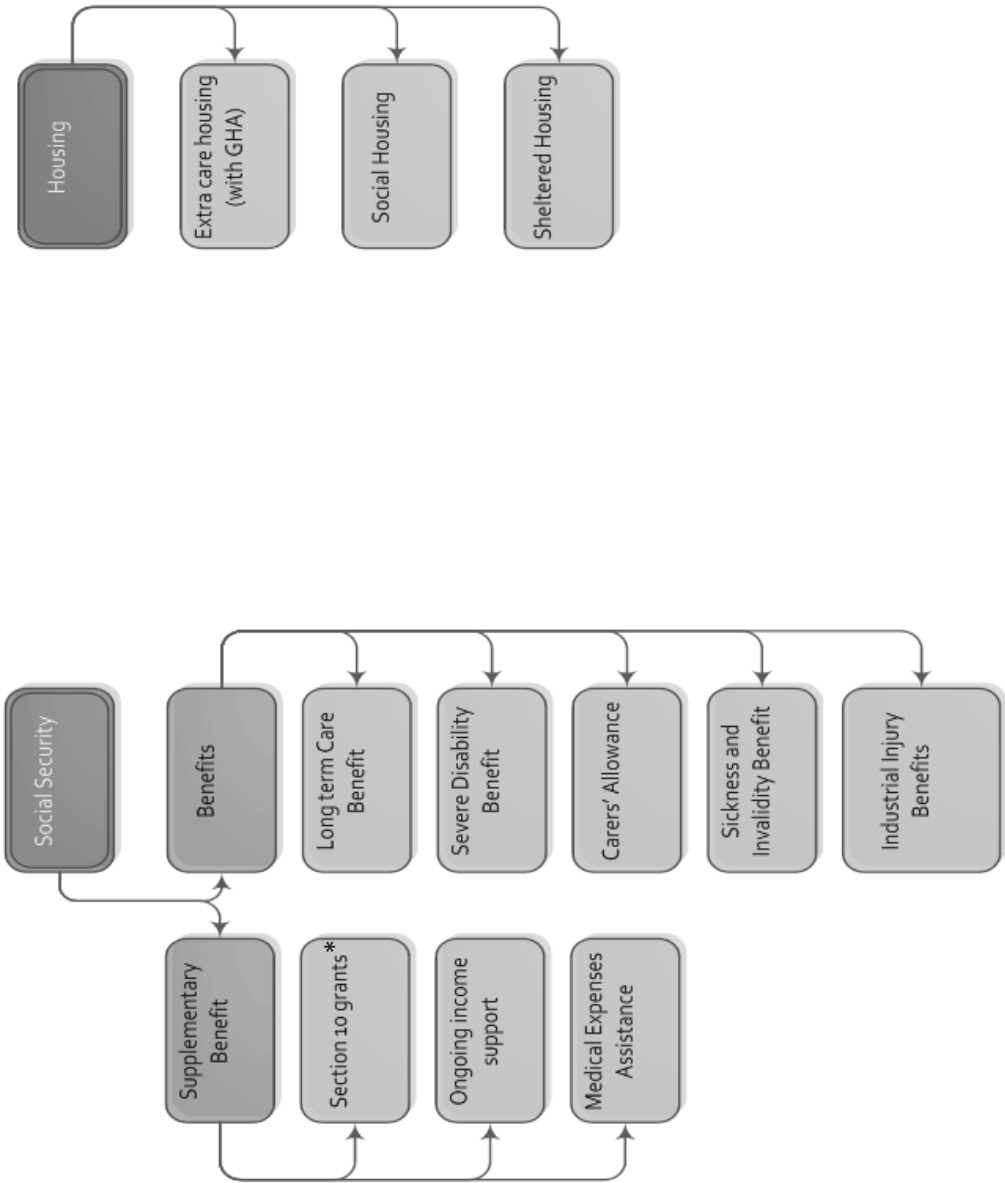


Figure 2C - continued: An overview of key public sector services for adults with long-term care needs



\*Section 10 - the Social Security Department can provide grants or loans towards the cost of purchasing equipment or adapting properties to make them more accessible to individuals with care and support needs. This is operated on a means-tested basis.

One of the key issues for the Working Party has been to understand better the level of coordination between services where an individual is in receipt of multiple services at the same time.

The following is a brief overview of the services provided by the public sector and the financial benefits available to support those with a long-term care need.

### **Severe Disability Benefit (Social Security)**

People who are living in the community (rather than in a care home, hospital or other institutional care setting) who are severely disabled and require help with personal care or who might be at risk if left alone for long periods, can apply for Severe Disability Benefit from the Social Security Department. This is a cash benefit of £100.45 per week (2016 rates), and is available to those with a household income lower than £93,000<sup>36</sup>.

In December 2014 there were 611<sup>37</sup> claimants.

Severe Disability Benefit is a non-contributory benefit, which means that it is funded by tax rather than Social Security contributions. If someone is claiming Supplementary Benefit (means tested income support) as well as Severe Disability Benefit, Severe Disability Benefit is not included in assessed income but is paid in addition to any Supplementary Benefit received.

### **Informal / family care – Carers’ Allowance (Social Security)**

When an adult has care and support needs it is often their immediate family or closest friends who help them. This can be their spouse/partner, parent, child or friend. The people who care for their family or friend are referred to as ‘informal carers’ or just ‘carers’. Current estimates suggest that there are between 2,000 and 4,000 carers in Guernsey<sup>38</sup>.

Carers of people claiming Severe Disability Benefit can apply for Carers’ Allowance if they care for more than 35 hours per week and are over 18. This is a cash allowance of £81.28 per week (2016 rates), and is available to those with a household income lower than £93,000.

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<sup>36</sup> Social Security Department (2015) “Severe Disability Benefit Rate” available at: <http://www.gov.gg/sdbenefitrate>.

<sup>37</sup> This figure includes some claims on behalf of under-18s.

<sup>38</sup> The Disability Needs Survey estimated 8% of households (2085 households) contained carers in 2012 (<http://www.gov.gg/disabilitystrategy>); In 2014 the Guernsey Healthy Lifestyle Survey (<http://www.cph.org.uk/wp-content/uploads/2015/01/Guernsey-Healthy-Lifestyle-Report-2014-12th-December-Final.pdf>) estimated that 5.7% of participants had caring responsibilities (expanded to the whole population this would mean 3,576 people); in 2011 the Housing Needs Survey estimated that 15% of households contained people with caring responsibilities – 3,847 households (<http://www.gov.gg/CHttpHandler.ashx?id=79858&p=0>). Confirming an exact figure is complicated by the fact that many people who care do not define themselves as ‘carers’ and might see their role as a normal part of family life.

In December 2014 there were 417<sup>39</sup> claimants.

Like Severe Disability Benefit, Carer's Allowance is a non-contributory benefit funded by tax rather than Social Security contributions.

If a carer is claiming Supplementary Benefit (means tested income support) as well as Carer's Allowance, then Carer's Allowance is treated as earnings. This means that £30 of Carer's Allowance and any earnings received per week can be received in addition to Supplementary Benefit, but not the full £81.28.

### **Community Health and Wellbeing Services (HSSD)**

Community Services provide care and support to people (age 18+) living in their own homes. The support includes services from a range of professionals:

- **Social Workers** - Professionals who are available to provide information about services in Guernsey and Alderney and to discuss with people which service may be appropriate for their needs, particularly regarding carer support and help to stay living at home. They call upon a range of expertise to assist with complex problems. They also undertake comprehensive assessments for people who require residential or nursing home care.
- **Senior Carers** - Home care workers who give help with personal care such as washing and dressing, going to the toilet, and provision of simple meals.
- **Carers (formerly Home Helps)** - Help with domestic jobs such as housework, cleaning, preparing simple meals and emergency shopping. There may be a charge for this service.
- **Community Nurses** - Registered Nurses who have completed a specialised course in Community Health Care Nursing.
- **Occupational Therapists** – Professionals who can assess a person's functional ability to complete activities of daily living, e.g. washing and dressing or meal preparation. They are able to give advice on appropriate aids and equipment or adaptations in the home to increase an individual's independence.

The following services are associated with the Community Services' team. Apart from the Health Visitor for Older People, all of these are available to working-age as well as older adults:

- **Lifeline Telephone System** - The Lifeline telephone system means help can be summoned in an emergency 24 hours a day by simply pressing a button on a telephone or on a pendant which is worn by the user. This is arranged via Sure Ltd. to whom a line payment is paid for the service.

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<sup>39</sup> This figure includes some claims on behalf of under-18s.

- **Shopping Service** – getting in food or provisions for people unable to do their own shopping as a result of illness or being housebound.
- **Sitting Service and Short-break Service**<sup>40</sup> – this service can help carers to have a break from looking after someone at home; day care may be provided for people who live in the community.
- **Transport Service** - mini-buses to help people get to and from Day Centres, HSSD-run residential accommodation, appointments, etc., and also deliver and collect community-based equipment. This service is run by HSSD and includes some wheelchair accessible vehicles.
- **Handy Person** - gives help around the house for minor home repairs and adjustments. There may be a charge for this service.
- **Meals on Wheels** - deliver cooked meals to those who need and request it. This service is provided by the Guernsey Voluntary Services (GVS) for a nominal charge. The GVS is grant funded by the States.
- **Rapid Response Team** - for short-term rapid access to additional support in crisis situations for people or their carers.
- **Health Visitor for Older People** - helps senior members (over 65s) of the community to lead as healthy a life as possible, both physically and mentally, and to improve the quality of their lives by helping them to maintain their independence and keep safe and well in their own home. There is one health visitor for people who are aged 65 years and over. The health visitor service is free and confidential.
- **Clinical Nurse Specialists** - give advice on issues like pain management, wound care, diabetes, continence and bowel management, heart and breathing problems, cancer care, and mental health.
- **Voluntary Car Service** - helps those who need it with transportation to medical appointments (e.g. an older person living in the community who has an appointment with a General Practitioner or with the Medical Specialist Group). This service is provided by volunteer personnel. It is not wheelchair accessible.
- **Palliative Care Team** - provides specialist support to people who are close to the end of their lives.

There are also private sector organisations that can help with some of the above, but there is no public funding available to support this at present.

In Alderney, nurses from the Mignot Memorial Hospital go out into the community to provide nursing services (injections, changing dressings etc.) as well as some personal

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<sup>40</sup> Previously 'respite care'.

care. The States of Alderney in partnership with Age Concern provide some “home help” support to meet other needs (there is also some private provision).

### **Older Adult Mental Health Services (HSSD)**

The Older Adult Mental Health Service specialises in dementia and other mental health conditions in adults aged over 65. The service includes:

- **A specialist Community Team** - who support those with dementia and Older Adult Mental Health issues. They can provide specialist advice, help with medication, and also offer some support for carers who have family or friends with dementia. The team give follow up support to people who have recently been diagnosed with memory problems or dementia.
- **A Memory Clinic** – helps with diagnosis for those with memory problems.
- The **‘Sarnia Ward’** - which is used for assessment.
- The **Duchess of Kent** - see below.
- The **Lighthouse Wards** -including one ward for complex physical conditions as well as mental health condition (see below).
- A **Day Centre** - for older people living in the community. This includes people with mental health conditions and people with physical conditions.

Some professionals from the Older Adult Mental Health Service visit Alderney regularly to provide specialist advice on the Island.

### **Adult Disability Services (HSSD)**

Disability Services include:

- A multi-disciplinary **Community Team who specialise in physical disability** – this tends to focus on specialist advice and support for working age adults with physical and sensory impairments and neurological conditions (whilst there may be some specialist support from this team for adults over 65, older adults needs are generally met through the Community Health and Well-being Service).
- A multi-disciplinary **Community Team specialising in learning disabilities**.
- A **Day Centre** - based at St Martin’s Community Centre, supporting people with learning disabilities.
- An **Accommodation Service** - provides accommodation for over 70 people with learning disabilities, and also offers some short-break placements.

- **A Positive Behaviour Support Team** - which helps learning disability service users and staff to manage and reduce challenging behaviour.

Disability Services support 128 people<sup>41</sup> who are 'active' on the Learning Disabilities' Register, as well as a number of people with physical impairments via the community team. The services work closely with those third sector organisations that also provide support to disabled people.

### **Mental Health Services (HSSD)**

As well as providing for acute mental health conditions, there are also some mental health services providing for those in need of ongoing support. This can include '**Intensive Outreach**' in the community as well as the '**Support Time and Recovery Team**' (STAR) that offers group and individual sessions to help maintain and improve the mental health of service users. The mental health service offers accommodation to some of its service users whose conditions have made it hard to find private sector accommodation.

### **Adapted housing and housing adaptations (Housing and Social Security)**

The Guernsey Housing Association (GHA) has a number of properties that are fully adapted for wheelchair users. The Housing Department will consider adapting social housing properties for tenants and have done this previously (or may be able to provide a better suited property if someone's needs change or develop). GHA and Housing Department properties are generally only available to social housing tenants who are not able to afford, or would have difficulty affording, accommodation in the private sector.

For people living in their own homes, Supplementary Benefit can sometimes offer financial support in the form of a grant or loan to help to cover the cost of home adaptations or the purchase of necessary equipment. This support may be available to someone who does not usually receive Supplementary Benefit and can afford to pay their day-to-day living costs, but cannot finance a lump sum for a house adaptation or large item of equipment.

### **Continuing Care at the Mignot Hospital, Alderney (HSSD)**

There is no nursing care home in Alderney, so people who need an equivalent of nursing care are cared for in the Mignot Memorial Hospital continuing care ward. This has 14 beds and over ten years (2004-2013) had an average occupancy of 77%. Whilst the service is mostly funded by HSSD, residents pay a fee equivalent to the Long-term Care Insurance co-payment. In 2016, the value of the weekly co-payment was £193.97 per week (section 2.2.3b below provides more information about the operation of the Long-term Care Insurance Scheme).

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<sup>41</sup> Figure accurate at November 2014, this includes individuals accommodated in the Learning Disability Accommodation Service.



### **Duchess of Kent (HSSD)**

Associated with the Older Adult Mental Health Service, the Duchess of Kent offers residential placements to cater for older adults with mental health conditions which may mean they need care and support for complex or challenging behaviour. This includes, but is not limited to, dementia. The service is not suitable for those with significant physical or mobility difficulties. There are 26 beds available, 2 of which are reserved for short-break care placements. This is where someone comes in temporarily to have a break from living at home, or to give the family or friend that cares for them a break, or both. This service is running close to capacity.

Whilst the service is mostly funded by HSSD, residents pay a fee equivalent to the Long-term Care Insurance co-payment (further information about the operation of the Long-term Care Insurance Scheme is available below and in section 7).

### **Lighthouse Wards (HSSD)**

The Lighthouse Wards (Hanois, Fougere and Casquets) are on the Princess Elizabeth Hospital site and provide specialist residential placements for people with complex physical needs. Their services are not age-specific but are need-led.

One ward is specifically focused on complex behaviour associated with mental health conditions (especially dementia); one ward is for people with both complex behaviour and physical needs; and another is solely for complex physical needs. The current capacity is 53 with 2 short-break care beds.

Average occupancy is high with the service usually running at or near capacity.

Whilst the service is mostly funded by HSSD, residents pay a fee equivalent to the Long-term Care Insurance co-payment (further information is provided about the Long-term Care Insurance Scheme below and in section 7).

### **Off-Island Placements (HSSD)**

People who have complex needs which cannot be catered for adequately on-Island can be offered an off-Island placement in a specialist centre in the UK. In 2014 there were 62 adults in placements for complex conditions in the UK<sup>42</sup>.

#### *b) Services delivered by the private and third sectors*

Whilst the Working Party has carried out extensive work to understand the range of care and support services provided or funded by the States, it has less knowledge of the range of care and support services provided by the private and third sectors.

The information available to the Working Party is as follows:

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<sup>42</sup> States of Guernsey Accounts 2014, p 69.

**Extra care housing (Guernsey Housing Association, Housing 21, Housing Department, and HSSD)**

Extra care housing is an alternative to residential care or community services. There are three extra care housing developments in Guernsey, providing independent living apartments with an onsite domiciliary care team and communal facilities (e.g. a café).

- ‘Rosaire Court and Gardens’, which is run by Housing and Care 21, contains 85 flats. Funding is provided for the domiciliary care service by HSSD.
- ‘La Nouvelle Maraitaine’ and ‘Le Grand Courtil’ are GHA properties with care and support provided by staff funded through the Housing Department’s General Revenue budget. The first phase of development saw the completion of 117 flats on these two sites. The second phase (approved by the States in March 2014<sup>43</sup>) is currently under construction. It will provide a further 45 flats on the two sites.

Most residents rent their apartments, though the GHA offers some units as partial ownership, and Housing and Care 21 offer some of their apartments for sale. The minimum care requirement for the extra care apartments is a need for 4 hours of care and support per week. The Housing 21 site at Rosaire is for people aged over 55 years, whilst the GHA sites are available for all adults, whatever their long-term needs. At the moment a range of adults are accommodated at the GHA sites including older adults and working-age adults with physical disabilities and learning disabilities. Neither is suitable for families with children.

**Supported housing provision**

The GHA has a small number of properties that have been purpose-built for wheelchair users. In addition, working in partnership with the Housing Department, the GHA has developed general needs social housing to a common design standard using the principles of the ‘Lifetime Homes’ Standard<sup>44</sup> to ensure that the design of new build social housing focuses on maximising independence, quality of life, and can accommodate increasing fragility.

Adopting the ‘Lifetime Homes’ principles means giving consideration to the following when developing or adapting a property. The principles include, but are not limited to, ensuring that there are:

- level access to doorways;
- wider internal doorways;
- larger circulation areas for wheelchair use;
- sockets and light switches at a convenient height for wheelchair users;
- a wheelchair accessible WC and shower room.
- incorporating wider car parking spaces; and

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<sup>43</sup> Billet d’État V 2014

<sup>44</sup> More information on the ‘Lifetime Homes’ Standard is available from [www.lifetimehomes.org.uk](http://www.lifetimehomes.org.uk).

- minimising distances from car parking to the home.

Many of the design principles, if incorporated at the time of construction, help to reduce the need for costly adaptations at a later date if an individual's mobility changes, for example.

Two sites, Courtil Jacques and Metivier House<sup>45</sup>, provide supported housing where residents live largely independently but have regular contact with, and emergency call to, the staff working at the Grand Courtil extra care site. This is intended for people with relatively low support needs who require some support but do not necessarily need the minimum 4 hours per week required for an extra care flat.

### **Private and not-for-profit residential and nursing care homes**

There are 21 care homes in Guernsey and one in Alderney run by the private and third/not-for-profit sectors with 631 beds in Guernsey and 24 in Alderney<sup>46</sup>. If an individual can afford to pay the full fees and wishes to pay the care home directly, they can arrange a placement for themselves without involving the States. However, many people seek financial help from the Long-term Care Insurance Scheme.

In order to obtain a funded placement, a Social Worker's assessment is submitted to the Needs Assessment Panel (NAP) which issues a certificate confirming the individual's need level. This sets out whether, in the view of the Panel, the person is suitable for a care home placement; and, if they are, whether they need a residential placement, a residential Elderly Mental Infirmity (EMI) placement (for people with dementia) or a nursing placement (for people with more complex health needs).

The States does not guarantee placements in care homes at present. Even if an NAP certificate is issued it is up to the individual to approach care homes to seek a placement. If a placement is found, the certificate entitles the individual to a significant contribution towards the cost of their care from the Social Security Department. Funding for this comes from the Long-term Care Insurance Scheme. People currently contribute between 1.3% and 1.6% of their income into the Scheme via their Social Security contributions. Access to the Scheme is based on five years' residency over a lifetime (with residency on the island over the 12 months before the claim) rather than on how much people have contributed to the Fund. Access to the Scheme is not means tested. Care home fees are structured as follows:

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<sup>45</sup> Courtil Jacques is managed by the Housing Department; Metivier House is managed by the GHA.

<sup>46</sup> Figures from internal data on registered beds, early 2015.

Figure 2D – Structure of care home fees

|  |   |  |   |
|--|---|--|---|
| <b>Long-term care benefit</b> (per week)<br>(from Social Security)<br>£429.87 (residential)<br>£566.37 (residential Elderly mental infirmity)<br>£802.55 (nursing) | <b>Co-payment</b><br>£193.97 (per week)<br>This amount has to be paid by the individual. If they receive a full old age pension, this should be affordable within the cost of the pension. If the person has no funds available Supplementary Benefit will often be able to pay the co-payment. | <b>Top up fee</b><br>Some care homes (but not all) will charge an additional top up fee that the individual has to pay. Top up fees vary from two to three figure sums per week. | <b>Personal expenses</b><br>Care home residents may also have personal expenses. For example they may need to buy their own toiletries, pay a hairdresser or pay for incontinence pads. |
|--|---|--|---|

Whilst care homes mostly cater for the general needs of people with conditions associated with ageing, one care home specialises in support for people with physical disabilities, another offers support to adults with mental health conditions, and one specialises in dementia care.

|                 | <b>Care homes</b> |  |
|-----------------|-------------------|--|
| Residential     | 13                | Residential care homes provide support to residents which can include food preparation and personal care. Some of these care homes are also registered for 'Elderly-Mental Infirmity', which means that they meet a certain standard to provide for residents with dementia that do not have nursing care needs. |
| Nursing         | 4                 | Nursing care homes are care homes with a registered nurse on premises who can undertake health related care like changing dressings as well as personal care and support with daily activities.  |
| Dual-registered | 5                 | Dual registered care homes have beds which are registered residential and others registered as nursing.  |

### Private nursing and personal care agencies

There are several private nursing and personal care agencies which can provide services to people in their own homes in Guernsey. The States does not currently have accurate information on the operation of these agencies. We know that there are both Guernsey-based companies and UK companies who provide live-in carers to Guernsey clients.

### Sheltered and retirement housing providers

There are retirement and sheltered housing providers in Guernsey which provide accommodation to people who wish to down-size. This kind of housing is aimed at older people and usually has a warden on site that residents can call on if they need assistance. However, the warden does not provide routine or personal care. Some establishments also arrange group social activities.

### **Voluntary and Community Organisations**

There are a number of community, not-for-profit, and voluntary organisations providing services within the community. These are often key to the range of services available and include:

- Information providers such as Citizen's Advice Bureau and Health Information Guernsey
- Community social, sports and activity clubs aimed at particular groups of older or disabled people or carers.
- Transport providers such as the Voluntary Car Service and St John's Ambulance
- Condition-specific organisations which can provide support groups and sometimes provide day centres, specialist support or assistance with obtaining equipment.
- Providers of day services and low-level social care, for example, the Guernsey Voluntary Service which runs Meals on Wheels.

It is evident from the above that whilst the private sector residential and nursing home care sectors are well developed in the Islands; there are fewer providers of domiciliary care.

Section 3 of this research report highlights the requirement to identify the various roles of the public, private and third sectors and to understand needs better in order to be able to develop the role of the private and third sectors in the provision of long-term care and support. **A key element of developing the strategic planning role of the States will be to enhance the knowledge of provision in the private and third sectors, and to consider ways to develop effective partnership with those organisations to deliver services that support the objectives of the Strategy.**

#### **2.2.4 Current arrangements for funding of long-term care: conclusions**

From its research, it is clear to the Working Party that the different sources and mechanisms for funding the services provided to those with enduring care and support needs have grown up in a haphazard and inconsistent manner. Funding largely depends on where people are accommodated and/or who provides the service.

Furthermore, the costs associated with long-term residential and nursing home care do not relate solely to the provision of care, but are a global sum for accommodation, food and other living expenses, together with care required by the individual. Here again, there is inconsistency in the treatment of the costs of different services.

The Working Party notes that all this inconsistency has the potential to, and often leads to, inequitable treatment of individuals with similar long-term care and support needs.

One of the key issues for the Strategy has been to understand better the current funding arrangements, in terms of who pays for services and who provides them, so that changes can be recommended to the existing arrangements to develop a clearer, fairer, and more sustainable means of providing and funding long-term care. Section 7 outlines these strategic funding issues and how they might be resolved.

## Section 3 – Developing the Care Community

**Recommendation 3(a):** To agree to establish and resource a function to plan strategically to meet the long-term care and support needs of the populations of Guernsey and Alderney.

**Recommendation 3(b):** To note that specifically this States' strategic planning function will:

- (i) Include development of the capability routinely to model and project future:
  - levels of need;
  - costs of care and support services; and
  - workforce implications.
- (ii) Work in partnership with the private and third sectors in each Island to focus on facilitating the development of cooperative relationships within the wider community of providers and funders, and to commission and facilitate the development of services within the private and third sectors to complement those provided by the States; and
- (iii) Investigate, in conjunction with the Committee for Employment and Social Security, the introduction of service level agreements with providers of care and support services specifying the quality standards expected where significant funding is being provided either directly or indirectly by the States.

Key data systems to inform long-term planning decisions are lacking. There has also been no clear, shared understanding of strategic direction for the care sector. Over time, services have developed in a piecemeal fashion, in the absence of clear information about need or demand or an overarching strategic framework. This has resulted in a lack of coordination and coherence and, if it continues, risks inefficient and ineffective responses to need at a time when resources will be tight.

To address this, the Working Party recommends that a strategic planning, commissioning and market development function should be established corporately within the States.

Sometimes we might think of care provision in terms of a set number of beds or services over which the States has control and is capable of arranging and structuring to suit its needs. All that is needed in this model is an idea of the most appropriate configuration for those beds and services. However, care and support in Guernsey and Alderney is not solely the domain of the public sector. Families, friends, community organisations, not-for-profit, and private sector organisations also play key roles in the whole picture. The relationships between the States, the private sector, the third sector and families are complex – forming a network of provision for individuals. This complex, multi-layered network of providers is not a straightforward hierarchical structure. The relationships between the different organisations and people involved can be as important to the effectiveness of the whole as the amount of service provided. To reflect the importance of taking into account the need to work with others who



provide care and support, and to consider how all of those involved relate to each other, we have termed this 'network' of many providers of care and support the 'care community'.

Strategic planning, commissioning and market development can be employed to develop the care community through gathering and providing information, comparing what is needed with what is being provided, and looking at how all of those involved are working together. In light of the feedback received from the consultation and the Working Party's own research, this section considers ways to strengthen roles within the Island's care community, and outlines in detail the role that should be developed within the States to coordinate and oversee the ongoing development of this sector, including strategic planning, commissioning and market development and regulation, and establishing more effective ways of working together with the private and third sectors.

**The public consultation document described the role of the States as a strategic planner as:**

- Monitoring the number of people in need of care and support, the availability of care and support services, the quality and safety of care and people's satisfaction with the care and support they receive.
- Actively supporting the development of appropriate services where there is not enough existing capacity, where there are service gaps or where there are problems with safety or quality.
- Coordinating care across the private, public and third sectors and making sure that referrals and links between services work effectively.
- Ensuring information is available so that people can find support when they need it and make informed choices.
- Broadening and developing regulation of all services within the care sector.
- Preventing needs from increasing through health promotion and the promotion of positive attitudes towards disabled people and towards ageing (discussed in section 5 below).
- Ensuring strategic management of population, land, and education to support growth in the care sector where needed.
- Ensuring that, where possible, the housing stock is built to accessible standards and that support to adapt housing to make it more accessible, where this is the best available option, is considered and addressed.

There is a particular need for the States to:

- (i) create a shared strategic direction;
- (ii) define and clearly communicate the role of the public sector;
- (iii) ensure that care across the sector has appropriate mechanisms for coordination in place;
- (iv) promote the development of services where there are acknowledged service gaps;

- (v) establish better procedures for collection, analysis and sharing of strategic information;
- (vi) plan for and feed social care needs into workforce, population, housing, and land planning policy development;
- (vii) plan for a coherent, sustainable financial future;
- (viii) ensure that the public and the professionals working in the sector have information about what services are available and how to access them; and
- (ix) focus on the quality of services provided by the care sector, through appropriate means of regulation and control.

### 3.1 The need for a shared strategic direction

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The care and support system is changing and developing constantly. Having a shared strategic direction and vision can help all of those working in the sector to coordinate development in a coherent way.

Whilst there have been policies and strategies developed in the different services and departments involved (Housing, HSSD, Social Security), there has been no overarching strategy for adult social care provision. Attempts have been made to create some links between care and support service provision and the care funding system; for example, there was some discussion of community care services in the Long-term Care Insurance Scheme Report (Billet d'État III, 2001). However, this has fallen short of a joined-up overview of service provision. There has been a lack of clarity about what the role of the States in care and support provision should be and why. There has also been a lack of clarity about the links between the various existing corporate and departmental strategies in different departments, their relationship to service-development, and their on-going relevance.

Melinda Phillips highlighted in her (2014) report that: "The strategic planning role of the States is underdeveloped with serious consequences. Forward planning is lacking because the States has been unclear about its role as planner or provider".

Getting a unified strategic direction right is important for the sake of the user experience of coordinated services; for the sake of efficiency to prevent duplication or spending on the wrong services; and to support private and third sector partners by being clear about our own role so that they can take this into account in their own planning processes.

It is important that this strategic direction is communicated and shared with all those involved in care and support outside of the States of Guernsey, where possible. The vision and outcomes outlined in this Report should help to provide the basis for establishing that strategic direction.

### 3.2 Define and communicate the role of the public sector, work in partnership with the third and private sectors

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*“We are glad that the Strategy acknowledges from the outset that there will be a need for real partnerships between the States, the private sector and the voluntary sector if major change is going to be achieved. Our members have emphasised that their relationship with the States does not feel like real partnership at present – there is a lack of information-sharing and involvement in service planning. This will need to change considerably in order for partnership working to be effective”.*

#### Ageing Well in the Bailiwick

One of the questions which the SLAWS set out to address was ‘who should provide services’. Phillips suggested that there was a lack of clarity about the role of the public sector and that *“as a consequence of this lack of clarity, the roles of the third sector and the private sector are unclear and under-developed.”*

The public sector can influence which sector provides services both by deciding what to directly provide, and by the design of the funding systems in place via commissioning, grants or benefits.

The Strategy emphasises the need for the public, private, and third sectors to work together more closely in ways that enhance the delivery of its priority outcomes.

It is also important that the role of the States of Alderney is clear, and that private and third sector organisations in Alderney are included in this picture. See section 4 below.

#### 3.2.1. Coordination and strategic development of the sector

Having considered the current situation and the research undertaken, the Working Party believes that the primary role of the public sector should be to have an overview of the sector and to facilitate the strategic development of the community of care providers. What this involves is discussed in 3.3-3.9 below.

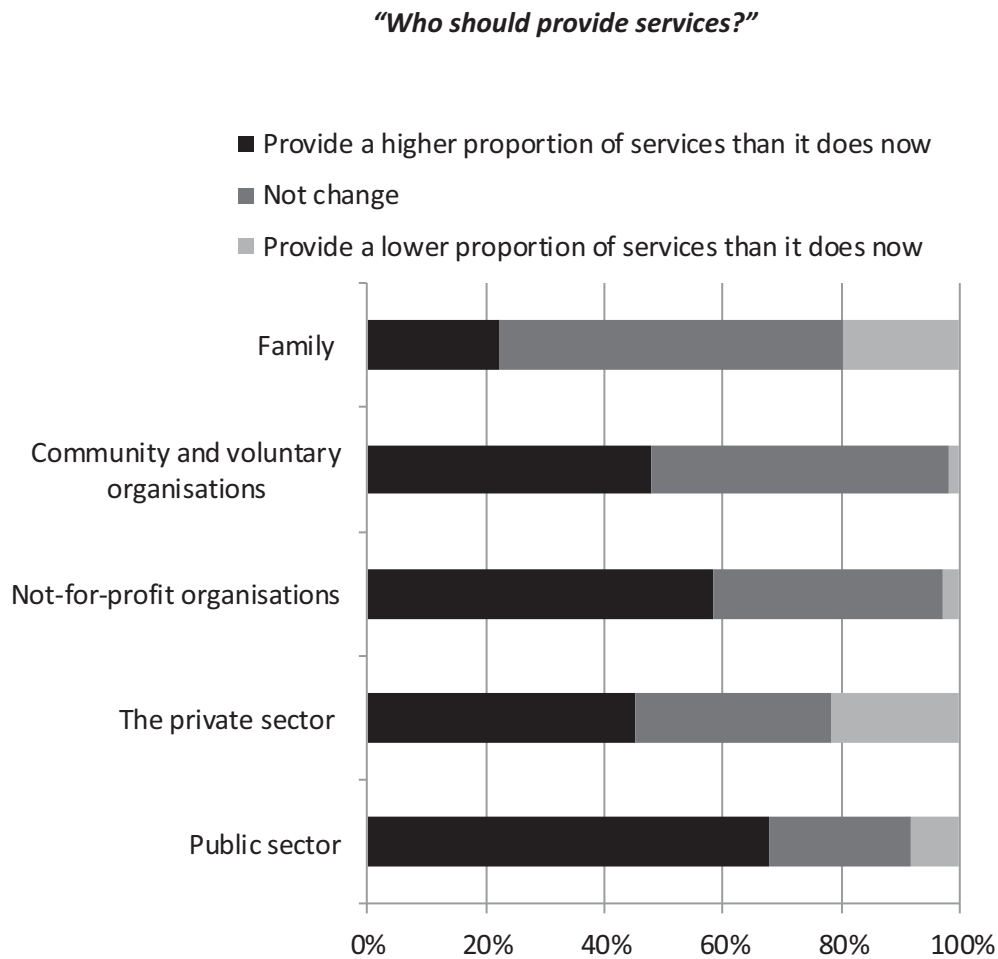
#### 3.2.2. Provision of services

The consultation asked whether the various sectors should be providing a higher or lower proportion of services than it did at present. There was, on balance, support for expansion in all sectors other than care provided by families. Whilst it was felt important that support for informal carers increase, it was also felt that there should not be an expectation of increased provision by families.

Respondents showed a stronger preference for expansion by the public sector and not-for-profit organisations than for expansion in the private sector – some commented that this was due to concerns about profit motivations in private sector organisations. Some respondents felt that the provider was not important as long as the required services were provided to a high standard. See **figure 3A** below.

Where services are provided by the States it is important to consider whether the departments providing the services are currently the best placed to manage the services in question. For example, at present HSSD bears some of the landlord duties for its residential homes and supported housing, and the Housing Department provides the care services within the GHA extra care housing developments. As part of the restructuring of departments in line with the States Review Committee, responsibility for the extra care housing and the development of any other specialist housing provision will fall with the Committee for Social Security and Employment. Work is underway to transfer landlord responsibilities for housing currently provided by Health and Social Services to the Housing Department (which in 2016 will also rest with the Committee for Social Security and Employment)

Figure 3A: Responses to consultation question 6



Further work needs to be undertaken to identify what services need to be developed and who is best placed to deliver them.

### 3.2.3. Partnership working

The consultation asked *“To what extent do you agree or disagree with the statement that ‘the States should be working more closely with the private and third sectors’?”* 90% of respondents agreed that the States should be working more closely with the private and third sector. Key stakeholders have commented that they feel that this is an area that needs improvement and development.

Partnership working can take many forms. It may simply involve communication with private and third sector providers and service users about what is needed, what is effective and what roles different parties are expected to play. In order to support partnership working it will be important to establish relationships with care providers, and to facilitate developments and connections between those managing and working in care and support.

Strategic planning should not be an effort undertaken by a specialist working alone; it should include the experience, knowledge and views of key stakeholders whose support for the Strategy is key to its success. True partnership working means co-development of policy and strategy to ensure that the Island communities, and not just the government, are working in the same direction and that the needs and concerns of Islanders are heard and responded to effectively.

However, partnership working could also involve joint working to deliver a specific service. There are some examples of this having already taken place. Notably the extra care schemes which have involved partnership working of the Guernsey Housing Association, Housing Department, Health and Social Services Department and some third sector and community organisations who are involved in the sites.

### **3.2.4. Supporting the third sector**

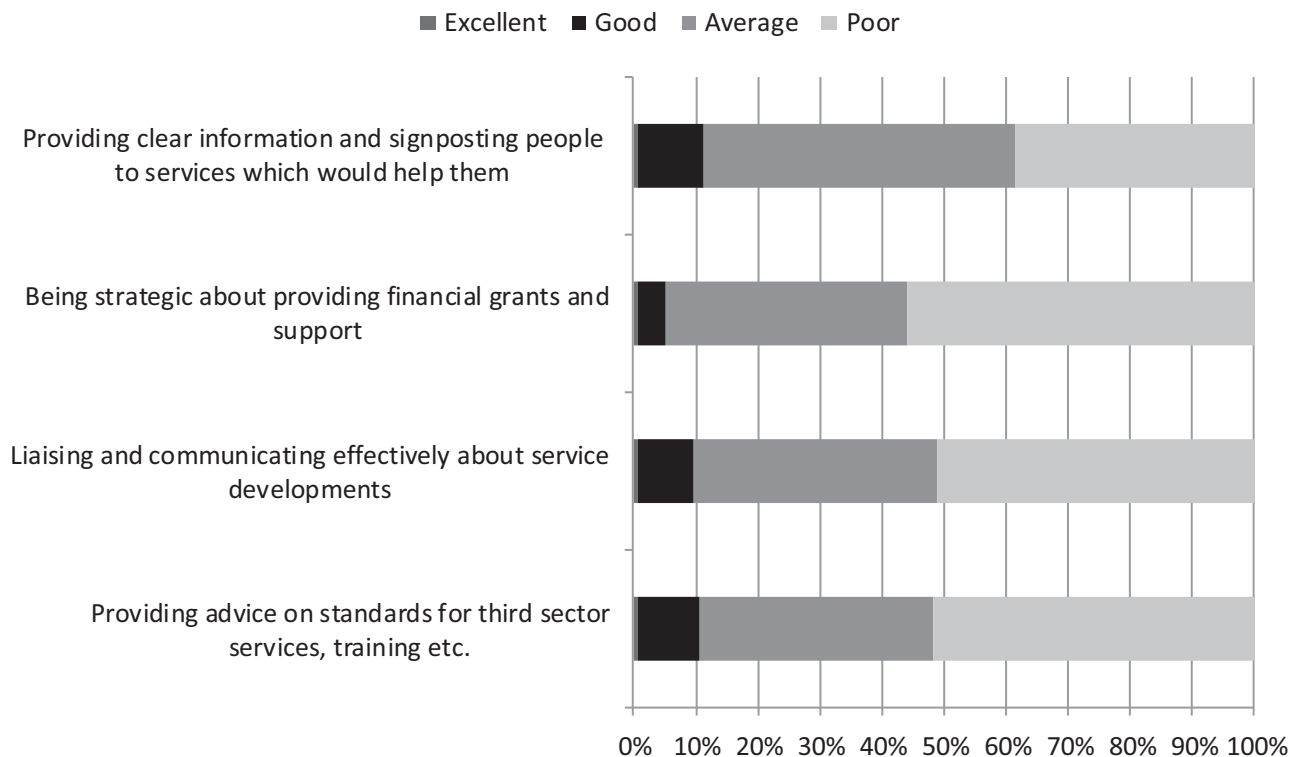
The community, voluntary, and charitable organisations are already actively involved in supporting people via day centres, support groups, provision of advice and equipment, and so on. These organisations contribute resources to care and support in the forms of volunteers' time and funds, which they raise independently. Whilst it may be possible for some of these organisations to expand the work they do, it is also important that the States supports them adequately and ensures they are effectively targeted and linked in with other service providers. Support may also be needed for organisations to develop the capacity and capability in order that they can do more to support people.

The consultation asked: *“How effectively do you think that the States supports third sector organisations (including not-for-profit organisations, charities, community, and voluntary organisations) in the following respects so that they can use their resources to maximum effect in relation to the provision of long-term care services?”*

Over half of respondents felt that the States' support to third sector organisations was poor in all respects listed apart from providing clear information and signposting people to services which would help them, where just over half of respondents felt that the States support to third sector organisations was average. However, out of those respondents who identified themselves as third sector community organisations, more than half felt that performance was poor in all areas with only one respondent (out of twenty six) rating any of the areas higher than 'average'. See **figure 3B** below.

Figure 3B: Consultation responses to question 7

***“How effectively do you think that the States supports third sector organisations (including not-for-profit organisations, charities, community and voluntary organisations) in the following respects so that they can use their resources to maximum effect in relation to the provision of long-term care services?”***



The Working Party believes it is important that the States supports voluntary organisations and does what it can to ensure these are effectively linked into the wider system.

This will be a further development of the States’ intention to uphold the ‘Third Sector Compact’<sup>47</sup> signed by the States and the Association of Guernsey Charities in 2014. As part of this compact the States agreed to:

- Foster and encourage the development of the third sector
- Work constructively with voluntary and charitable sector organisations
- Provide clear, concise and up-to-date information on its services
- Involve the third sector in the review of existing services and the development of new services

<sup>47</sup> Social Compact, 2014, Available at: <http://www.gov.gg/article/114369/Chief-Minister-addresses-the-Association-of-Guernsey-Charities-and-the-agreed-Social-Compact>.



- Use commissioning and procurement processes that are proportionate to the size and capability of respondent third sector organisations
- Use simple and clear agreements to establish working arrangements
- Respect the third sector's right to express opinions
- Provide the third sector with a single point of contact to resolve any difficulties they may experience

The third sector agreed to:

- Provide information that is clear, concise and easy-to-find
- Work co-operatively with the States
- Demonstrate proper governance and risk management
- Acknowledge the role and support of the States
- Recognise accountability to the taxpayer
- Work with other voluntary and charitable sector organisations

### **3.2.5. Service Level Agreements**

Service Level Agreements (SLAs) are agreements between the States and organisations that provide services stating what it is expected that the organisation will provide in exchange for funding. At present, only some of the services which are provided by the private and third sectors with public funding are provided under an SLA.

Implementing SLAs with more providers would allow for greater clarity about roles and expectations, as well as allowing for increased accountability. They could provide an opportunity to influence the shape of services provided by the third sector to ensure that these meet identified needs. This should be included in strategic planning.

## **3.3. Co-ordination**

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Many individuals who have long-term care needs will be in contact with several services, not just one service. It is vital that where someone is supported by several services that these services are coordinated around the individual to provide joined-up support. This is important both for ongoing service provision (for example, someone receiving support from community services and older adult mental health services), but also where someone is discharged from hospital and needs temporary support during their recovery time. Ensuring that services are coordinated and work well together should be part of the role of the States in its 'strategic' role.

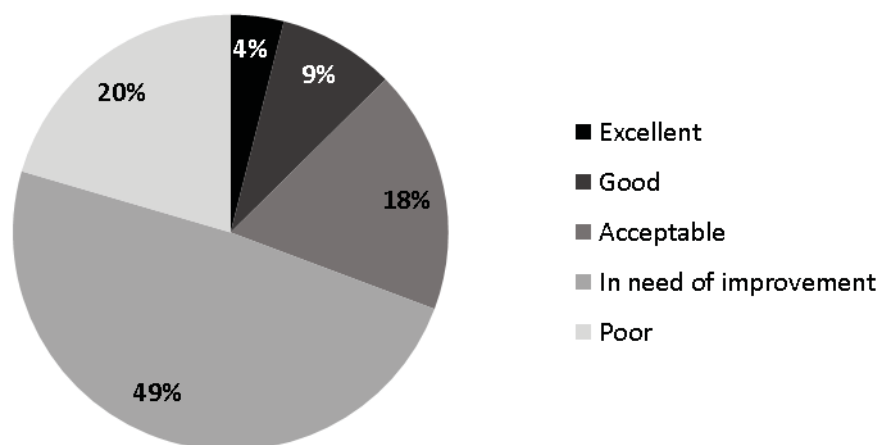
Phillips (2014) noted that there were issues in Guernsey related to the coordination of services. She felt that this was partly due to the lack of agreed data sharing processes and the complex funding arrangements. She was particularly concerned about the need to link physical and mental health services together.

Services need to ensure that they are coordinated not just within the States, but across the public, private, and third sector. This includes, for example, ensuring that GPs, the Medical Specialist Group, the hospital, community services, care homes, and community support groups are all linking effectively together in the interests of the people that they are serving. The States has a role to play in identifying where operational delivery systems are not supporting coordination and what needs to be done to correct them.

The consultation asked: *‘Where receiving support from multiple services, how well coordinated was the support you received?’* (Question 15). The majority of respondents (69%) felt that the coordination of the support they received from multiple agencies was “in need of improvement” or “poor” see **figure 3C**:

**Figure 3C: Consultation responses to question 15**

*“Where receiving support from multiple services, how well coordinated was the support you received?”*



The Working Party believes that the best way to address existing issues with coordination is as part of the wider work to take a strategic overview of the whole sector, supported by data gathering (discussed below) and for service managers to bring service coordination into consideration when managing their operational planning. Proactive care coordination should also be pursued (discussed below in section 6).

### 3.4 Promote the development of services where there are acknowledged service gaps

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Where there are gaps in services the States should take a role in ensuring that services are developed to meet those needs. This may not mean providing the services - it may mean working with partners to expand or modify existing services, or to develop new services. In order to identify gaps effectively, information needs to be gathered from both those using services and those working in services on a routine basis, as well as considering trends in service user numbers.

Commissioning skills is an area where Phillips identified that there was a lack of capability in the States of Guernsey. She defined commissioning as:

*“**Commissioning** is a term that has developed in procurement of goods and services to define tools that can be used to tender or negotiate goods or services that are fit for purpose at best cost and with able providers. This can be by tender or negotiation.*

*The principles of good commissioning are to:*

- *Understand the needs of users and others by ensuring that, alongside other consultees, you engage with the third sector organisations as advocates to access their specialist knowledge.*
- *Consult potential providers, both third sector and public sector, well in advance of commissioning new services and working with them to set priority outcomes for the service.*
- *Put outcomes for users at the heart of the strategic planning process.*
- *Map the fullest possible range of providers with a view to understanding the contribution they could make to deliver the outcomes.*
- *Consider investing in building the capacity of providers if necessary.*
- *Ensure that contract processes are transparent.*
- *Set outcome measurement rather than specify every detail to ensure innovation in design and construction or service design.*
- *Monitor through outcome achievement not detailed design.*

*Commissioning has been seen as the opposite approach to micro-managing every detail of the provision or service to be tendered and then relying on price to place the contract. It encourages innovation, the development of an expert market and provides the best information of how the service should perform.”*

**There is currently a lack of commissioning skills within the States.** Approaches to managing publicly-funded service provision are varied. This will need to be addressed corporately going forward.

In order to develop partnership working a good knowledge of the sector will be needed, not only knowing what is provided, what demand is, who has capacity to increase provision, but also to understand the barriers and enablers to service growth. In other words, a sound knowledge of what is needed to develop the market for care provision will be needed. **In order to take this forward, the Working Party believes specialist skills will need to be engaged in**

order to analyse the current situation and identify opportunities to develop the care 'market'.

### 3.5. The need for improved strategic information

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Currently there is limited information available about the level of need in the community or about how satisfied service users are with existing services.

**Information about the level of need:** Whilst there is some information from the Disability Needs Survey (2013) and from evaluations undertaken by individual services, there is no clear, joined up analysis of this data and there remain significant information gaps.

**Information about specific need groups:** we lack key information about the prevalence of certain conditions which indicate specialist needs – for example, the number of individuals with dementia in the islands. This is partly to do with the sharing of aggregated data between different parts of the health and social care system.

**Information about the number of service users and the availability of care and support:** Most services do collect some data on the number of service users. However, there are a number of data systems used within Social Security, HSSD and Housing, and it is not always possible to identify where the same individual is accessing multiple services. Consequently, we do not currently have a joined-up picture of service use. In addition, we do not have a clear picture of the number of people receiving care and support from the private and third sector.

**Information about the future:** the Working Party has undertaken some projections of the future demands for services and the attached cost implications as part of its research; however these remain incomplete, are based on current service structures, and are not undertaken routinely. There are regular reviews of the viability of the Long-term Care Insurance Scheme against future population projections (which in recent years have been undertaken by the UK Government Actuaries Department). However, the General Revenue spend on care and support services is not projected regularly. Consequently, there remains uncertainty about the implications of policy decisions on future costs. (Information on projections undertaken by the Working Party is included in section 7).

**Information about the cost and viability of providing services:** some information is available on the cost and cost-effectiveness of services. New benchmarking information has become available following some work undertaken by BDO on HSSD services, but there is not a clear idea of what a baseline cost for care in care homes in the private and third sector should be, which will be critical to some of the funding proposals set out in section 7.

**Information about performance and service user satisfaction:** there are not yet Key Performance Indicators in place for this Strategy or for all of the services which are related to care and support provision, or clear coordinated systems for identifying service user satisfaction.

Consequently, data is incomplete and not systematically collected or analysed. Without this data it is difficult to formulate an evidence-based policy. Information systems within the States need to develop in order to support this analysis.

The need for better data systems has long been recognised. As part of the 2001 States Report on the Long-term Care Insurance Fund<sup>48</sup> it was proposed that Social Security establish a 'Minimum Data Set' system to monitor the need and provision of long-term care. This system was never established.

Phillips summarised in her report that: *"there is little systematic capture, collection and analysis of data to be able to plan services. Both public and private sectors are keen to develop their services but they need to know what services are needed before they can respond."*

More respondents to the consultation felt that the States monitoring of core data was poor or below average than felt that it was good or excellent (see question 6).

Data sharing between health and social care providers was also raised as an issue from the perspective of some professionals not having access to medical records when the patient wished them to have a full history. This is largely due to complex data protection issues surrounding medical records. Significant progress towards a more person-centred system could be achieved if these data protection issues were addressed in an appropriate way to allow for greater ease of patient data sharing between professionals in appropriate situations.

## 3.6 Linking to other strategic areas

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As acknowledged in 3.4 above, strategic decisions made in other policy areas can create barriers or enablers for the growth of the care sector. These include considerations about workforce, population, housing, and land-planning. Ongoing work on strategic planning of care services needs to link effectively with these other areas of work in order to ensure that the whole Strategy is sustainable.

### 3.6.1. Workforce implications

Supporting professionals working in the care sector is of critical importance to the success of the Strategy. The care workforce is important because:

- the quality of interaction between staff and individuals with care and support needs is key to providing effective, good quality services;
- skills and training is important to help staff to perform optimally, understand the conditions of the individuals that they work with, and maintain their own wellbeing and safety;
- maintaining the right mix of skills in the workforce will be key; and

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<sup>48</sup> Billet d'État III, February 2001.

- the ageing demographic will put strain on the care workforce from three directions – increasing demand for services (i.e. increasing demand for staff), decreasing the proportion of individuals who are of working age (i.e. decreasing availability of staff), and increasing international competition for care staff.

In order to obtain the workforce we need in the future, it will be critical to understand the demand and supply issues in the labour market and give proper attention to training opportunities, recruitment and retention of staff. This is not an area which the Working Party has had significant time to consider; indeed, it was out of scope for its deliberations. However, it is important to highlight as it was consistently raised throughout the consultation.

As part of the strategic planning role that the States needs to develop, it is important that human resources are taken into account when understanding the future of the sector rather than focusing purely on funding, not least because most long-term care services are labour intensive and staff costs represent the majority of expenditure. When projecting the future cost of services it will be essential to understand what that means in terms of the number of staff required for those services to function. The two are clearly inter-related (a topic covered in more detail in section 7), since staff shortages will drive wages and costs up, and increase the risk that the system will become financially unsustainable.

The importance of the quality of interactions between staff and service users is discussed in more detail in section 5 below.

### **3.6.2. Population**

It is important that strategic planning of health and social care links into population policy, particularly with regards to the demographic balance of the population and the maintenance of a workforce large enough to provide for Islanders' care and support needs.

### **3.6.3. Housing**

Housing provision needs to form part of the wider strategic picture; both in terms of the provision of supported housing (discussed further in section 6 below), but also in terms of increasing the stock of housing which is specially adapted for disabled people – for example fitting properties with appropriate lighting, acoustics, colours or materials to minimise sensory overload for people with autism; increasing the stock of housing for older people which supports people to downsize into properties which are easily accessible and easy to navigate; and supporting people to adapt their existing houses, where appropriate, so that needs can be met by creating more enabling environments.

### **3.6.4. Land planning**

Land planning policy should support the development of required supported housing and care homes in appropriate locations, but there is not yet sufficient data for the Strategy to specify what is needed and where. Ongoing work needs to be in dialogue with strategic land planning to ensure that development is facilitated where needed (discussed above in section 2 of this report).

### 3.7. Financial planning

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It is important for the future of care and support on the Islands that the whole of the care sector is financially sustainable. This means not only ensuring that States funding is sustainable (discussed in section 7), but also ensuring that private and not-for-profit providers remain viable and do not go out of business. Consequently, it is strategically important, not only to have a view of the finances of the Long-term Care Insurance Scheme, but also to have a good understanding of the costs and profitability of private sector services.

Consideration of finances should also be forward-looking. As part of its strategic planning role, projections of cost should be undertaken for the whole system regularly, allowing adjustments to be made to make the system sustainable. The work which needs to be undertaken in the first instance to address sustainability issues is outlined in section 7 below. However, it is important that on an ongoing basis there are routine financial projections which feed into the wider strategic planning undertaken.

### 3.8 Information and advice for service users

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A major area of concern from the public consultation was that members of the public and professionals working within the sector found it hard to access information or advice about what services and support were available on the Islands. This sometimes meant that individuals only found out that they could access support some time after the support was needed. Undoubtedly, ensuring that there are effective streams of information about service provision should form part of the overarching role of the States. For many, the point at which care and support services are sought out is often following an illness or crisis, which has already placed the individuals involved under significant stress. It is important that uncoordinated service structures do not compound this stress by lack of information or confusing information - there is a need for a clear path to access advice about how to best obtain the support any individual needs.

In part it is hoped that this will be addressed by the introduction of proactive care coordination discussed in section 6 below.

However, there is already some work underway as part of the Disability and Inclusion Strategy (Billet d'État XXII of 2013) which directed the Policy Council to "develop information for disabled people and carers for a one off cost not exceeding £70,000". The recent update on the Disability and Inclusion Strategy (included in Billet d'État XX of 2015) identified that the current priority for this workstream was "to establish a website dedicated to providing information on services for disabled Islanders and carers".



### 3.9 Regulation, safeguarding and the need for information on the quality and safety of care

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#### 3.9.1 Regulation of care and support services

Regulation of health and social care services are key to ensuring that people are safe, can make informed choices, and have confidence in the services that are available to them. It is important that the States can gain assurance over the safety and quality of its own services and those provided in the private and third sector in order to effectively manage risks to the wellbeing of the public.

At present, care homes are inspected and regulated by HSSD under the Nursing Homes and Residential Homes (Guernsey) Law, 1976, but there is no independent inspection of private domiciliary care services, services managed by HSSD, extra care housing, acute health care and primary health care services. Work is underway to expand the regulation of health and social care services to cover these areas and ensure that care is safe and of adequate quality. Whilst currently being progressed by HSSD, this work is vital to the Strategy.

A new model for the regulation of health and social care is being developed, in a Guernsey context, to ensure that quality assurance and best practice are at the heart of local services. Quality standards will be developed with key stakeholders having reference to the standards used by other jurisdictions such as the Care Quality Commission, Scottish Care Inspectorate and various international Quality Assurance systems. Initial consultations have suggested that there is support from health and social care providers for expanding regulation to cover all areas of care provision.

From the care provider's perspective, independent regulation will have advantages in providing a level playing field for all health and social care providers, building confidence for service users and their families, being able to evidence or demonstrate good practice in cases of legal challenge, and the regulator providing guidance and support for management to improve the quality of their services. This in turn will reduce the number of cases of abuse and neglect and improve protection for the most vulnerable sector of our community.

#### 3.9.2 Adult safeguarding

Adult safeguarding is about working together to manage risk to ensure that abuse or neglect of adults are prevented where possible, and responded to in a timely, proportionate manner where they do occur. This is also of key importance to the Supported Living and Ageing Well Strategy. People with care and support needs and their carers may be at risk of abuse or neglect and it is important that those who are in contact with them respond appropriately to any signs of something untoward occurring. The Disability and Inclusion Strategy (Billet d'État XXII of 2013) directed:

the Home Department to lead the development of policies and procedures for safeguarding vulnerable adults in conjunction with other States Departments, reflecting those already in place for children

This work is underway but is now being led by HSSD. Its implementation is of key importance to the Strategy and forms part of the role of the States in strategically managing the care sector.

### 3.9.3 Domestic Abuse

A third area of risk relating to safety which needs to be managed is domestic abuse. Where people are cared for at home by friends or relatives there is a risk that in some cases the relationship will be or become abusive. In this situation there needs to be appropriate support for the individuals involved. This means that domestic abuse planning and provision needs to be aware of the abuse of older people, carer abuse and the fact that individuals with disabilities are at higher risk of abuse.

The need for coordinated work was recognised in the Domestic Abuse Strategy for Guernsey and Alderney 2016-2020 which was considered by the States in Billet XXIII of 2015. This needs to be progressed alongside the work to support informal carers outlined in section 6 below.

## 3.10. Summary

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74% of consultation respondents agreed or strongly agreed that the States should be a 'strategic planner'. Most respondents considered the States' performance was 'below average' or 'poor' at the various aspects of this role at present.

As set out above, there is currently a lack of regulation; a lack of strategic information; a lack of information available to people with care and support needs; and no coherent overview of what is needed in the system.

In order to address the range of issues highlighted, the Working Party recommends the **establishment of a strategic planning and commissioning function** within the States to support the effective implementation of the Strategy. There is a need for dedicated resources to be available to develop the capability to model and project need levels, and to initiate and coordinate change, not only across the States but also with the private and third sectors.

Whilst strategic planning will not resolve the challenges that the Islands face, the development of improved information to inform decision making should improve the ability of the States to identify and respond to any changes which present risks to the provision of high quality care and support in an effective and timely manner.

Although it is not easy to place a figure on how much value will be generated as a result of better strategic planning, the Working Party considers that there is significant potential for value to be gained by mitigating cost increases; managing funding streams; ensuring that referrals and links between services work well; and increasing the effectiveness of service provision. There is also potential for significant improvements in service quality.

The Working Party considers that the lack of strategic oversight for the provision of long-term care and support services is one of the core weaknesses in the present system. Without that

strategic overview being established to understand needs better and to direct resources accordingly, there is a high risk that resources will be misdirected.

## Section 4: The provision of long-term care and support services in Alderney

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**Recommendation 4(a):** To direct the Policy and Resources Committee to carry out research into the specific needs and requirements in Alderney, with a view to a report on any modifications of the Strategy for Alderney being presented to the States by the end of 2017.

Although the Islands are closely linked, the research informing the development of the Strategy has identified some important differences between Guernsey and Alderney, which need to be taken into account to provide an effective Supported Living and Ageing Well Strategy to Alderney residents.

The consultation process identified that whilst some Alderney residents felt that specific consideration and focused attention needed to be given to Alderney and its unique challenges, the majority felt that it was unnecessary for Alderney to be singled-out for separate consideration and would rather that the Island be incorporated into the whole Strategy rather than be seen as an 'add-on'.

Whilst the Working Party acknowledges that the principles of the Strategy and the proposed outcomes for individuals should be the same regardless of which Island someone is resident, the consultation process also identified some issues that are specific to Alderney which may need special consideration. These are described below.

### 4.1. Feedback from the public consultation

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Although the sample size for the responses from Alderney was small (with only 12 respondents identifying themselves as living on, or operating in, Alderney), some differences emerged. **It is not clear whether these are due primarily to the sample size or if they are due to differences in views between the Islands' populations.**

In general, Alderney respondents:

- showed weaker support for the underlying principles;
- showed less support for working in partnership with the third and private sector;
- showed stronger support for increased public sector provision (as opposed to private, or not-for-profit);
- tended to rate experience of services lower;
- reported less difficulty with social attitudes about age;
- felt that care staff were more likely to enable the person they cared for rather than do things for them compared with respondents as a whole; and
- were marginally more supportive than respondents as a whole of incorporating the value of property in means-testing (see section 7.5.4).

A number of further comments were received, these included:

- that it would be important to be clear about the role of the States of Alderney in the strategic planning of, and provision of, care and support services;
- travelling to and from appointments in Guernsey and accompaniment for this travel, where necessary, was a concern, as were arrangements for family members visiting relatives in hospital in Guernsey;
- the Home Help service, which, in Alderney, is privately funded, was reported to play a key role for Alderney residents with care and support needs;
- there were concerns that with younger people leaving the Island there could be less availability of informal care for older residents with care needs;
- there was a suggestion that professional services could visit more frequently or that telehealth/telecare services could be arranged to allow more frequent meetings via video-link in-between visits to the Island; and
- there were concerns that benefit rates were based on the cost of living in Guernsey.

In addition to the public consultation responses, the following issues had also been drawn to the attention of the Working Party:

- There is **limited statistical information** for Alderney concerning those people who require health and social care and the type of care they need. Further service mapping and data collection is required to better understand needs;
- There is **limited information and advice** in Alderney for those requiring care and support and their families, and it is not readily accessible or available to those who need it most;
- **Suitable accommodation and supported living options** are sparse in Alderney. More work is required to understand needs better and to scope out requirements and areas of shortfall. The Alderney Housing Association has developed some accommodation which is accessible for people with mobility issues however, there is no, nor any plans for, supported housing.
- **Communication** between various organisations and between services in Guernsey and Alderney can be somewhat disjointed;
- The **needs of Alderney residents with advanced dementia or Alzheimer's** cannot be met in Alderney and people are, therefore, cared for in Guernsey. This results in separation from their spouse, family or friends;
- **Assessing the needs of Islanders to allocate appropriate care and support is often slow**, as the Social Worker carrying out assessments is not based in Alderney. This has sometimes resulted in a delay which was felt to put an individual in danger, and also places a higher level of responsibility on those trying to help with limited access to services;
- There are **very limited short break services in Alderney**, provided only by the Connaught Care Home and the Mignot Memorial Hospital in emergency situations;

- **Services provided out of regular working hours are very limited.** Age Concern and the district nurse provide some cover, although the resources to do so are limited; and
- Patients in need of **rehabilitation** are able to remain in the Mignot Memorial Hospital for longer periods of time before discharge than in Guernsey, due to lower bed occupancy levels. There are better and more cost-effective ways to support rehabilitation through community care options than in a hospital setting.

## 4.2. Conclusions

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As described above, particular topics which have been identified as requiring further consideration in relation to the provision of long-term care and support services in Alderney include:

- The remoteness of Alderney and the challenges this presents for service delivery;
- How the States of Guernsey, States of Alderney, private, and third sectors can work together in Alderney to support people with long-term care and support needs;
- How to improve services at times of transition, for example from hospital to home;
- Travel for appointments, and allowances for passengers<sup>49</sup> accompanying patients to such appointments;
- The restricted availability of services and the opportunities to improve service delivery. This should include consideration of the use of innovations, such as telehealth;
- Clarifying role definition and responsibilities between the States of Guernsey and States of Alderney, especially with regard to strategic planning; and
- The availability of data about services and needs relating to Alderney.

In order to take all of the above into account, it is considered that a dedicated piece of work is necessary to carry out further research into the needs and requirements in Alderney.

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<sup>49</sup> The Social Security Department provides a 'Travelling Allowance Grant' to cover the costs of inter-island or off-island travel to medical appointments. Under certain circumstances this Grant provides cover for an individual to accompany the person travelling for treatment, but this usually only covers professionals where the individual concerned is an adult. If a non-medical escort is approved by a doctor then the individual can apply for 'Travelling Expenses Assistance Scheme', however this is means tested. There are some concerns that this is not sufficient to support Alderney residents to accompany their family members when they travel to receive treatment in Guernsey or the UK.

## Section 5 – Social Attitudes

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In a Strategy such as this, it is easy to focus on the obvious areas of service provision and funding and neglect the less tangible issues about how individuals are treated by society and by those who deliver health and social care services. Indeed, the focus in this Strategy on worsening dependency ratios and the greater likelihood of older people to have long-term care and support needs, while necessary and factual, themselves create and reinforce stereotypical references to older people as being inactive, immobile, and incapable of independent living, and thus a burden on society. Similar attitudes are also pervasive with regard to younger adults with long-term care and support needs.

So whilst most people probably think of legal cases of discrimination at work or in society when they think about prejudice, attention needs to be given to the subtler ways in which social attitudes affect people's lives. Some investigation needs to be given to the dynamic day-to-day way in which people's assumptions and expectations can limit the opportunities available to others. This could be due to health condition, disability, age, class, sex, gender, sexuality, race, nationality, religion or for other reasons. Examples might include:

- cases where same sex couples are not given the same opportunities to be together in care settings as opposite sex couples
- cases where an individual's gender identity and clothing choices are not respected by carers
- assumptions about whether older people wish to use the internet
- assumptions about whether people with disabilities wish to have access to sports facilities
- assumptions that people who use a wheelchair are completely incapable of walking, or that they have a learning disability or cognitive condition.
- assumptions that people with learning disabilities are incapable of making any choices for themselves.

Work needs to be undertaken to address these attitudes. Some areas related to equality are already being addressed. The Disability and Inclusion Strategy, for example, was unanimously supported by the States in November 2013 and work is underway within this Strategy to address some of the issues which individuals with disabilities face on a day-to-day basis. The work undertaken within the Equality and Rights Programme, of which the Disability and Inclusion Strategy is a part, will be key to ensuring that these attitudes, and concrete instances of discrimination, are addressed.



## 5.1. Attitudes towards ageing

**Recommendation 5a): To direct the Policy and Resources Committee to investigate the impact of ageism in Guernsey and Alderney and how it could be addressed, reporting to the States with its findings and any recommendations no later than February 2019.**

Ageist assumptions in our society can lead to lower quality of life, a less inclusive society, and higher demand for formal support. Of the consultation respondents, 75% felt that they sometimes, frequently or always found that the assumptions people made about what they wanted or were interested in based on their age made it more difficult for them to do what they wanted.

We are all ageing. “Ageing well” is not just about supporting older people but about how all of us live across our life course and the expectations we have of different stages of our lives. Ageism can happen to both younger and older people. It occurs where unspoken assumptions and stereotypes are used to make judgements about what people want or need without seeing them as individuals with diverse interests: this is entirely in conflict with the notion of ‘person-centred’ care and support.

Arguably society tends to see old age as a time of increasing ill-health and dependency<sup>50</sup>. This is clearly not the whole picture. Whilst, in the 2013 Guernsey Healthy Lifestyle Survey, older people were more likely to have multiple health conditions, over 65s reported higher mental wellbeing than the working age population. Many older people, whilst not working, contribute significant time to caring for grandchildren, caring for their friends or partner, or undertaking voluntary or community work. Old age in the 21<sup>st</sup> century can offer new opportunities to pursue interests, to lead a good and fulfilling life and contribute to the community.

The way that ageing is thought of and spoken about can limit what individuals aim to achieve and what opportunities they are offered. If the expectation is that old age will result in fewer opportunities to socialise, declining health and poor quality of life, there is a risk that this will become a self-fulfilling prophecy. Opportunities for older people to socialise, challenge themselves, exercise and pursue their interests are important to maintaining their health and their independence. They are also important to ensuring that the health and social care system can operate in a financially sustainable manner.

On the other hand, there is a risk of taking this too far: whilst optimum wellbeing is one of the aims of this Strategy, there is a risk in assuming all older people will be capable of independence if encouraged and supported - this needs to be tempered by the reality that many older and working-age adults genuinely do require care and support. It is, therefore, important that ‘ageing well’ is focussed on helping people to live life to the full within their specific circumstances, rather than aggressively pursuing the idea that older people who have care and support needs have ‘failed’ at independence, or to create a blame culture in which

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<sup>50</sup> Bond, J. and Cabrero, G. R. (2013) “Health and Dependency in Later Life”, in Bond, J.; Peace, S; Dittmann-Kohli, F.; Westerhof, G.J. *Ageing in Society: European Perspectives on Gerontology*, Third Edition, London: SAGE.

individuals feel that they are held morally responsible for their ill-health due to not exercising enough, eating healthily enough and so on<sup>51</sup>.

Older people are a diverse group with diverse interests. Whilst older people themselves might hold expectations about their lives based on ageist assumptions, it remains important that any work looking to address ageism in old age needs to be built on older people's experiences and that all involved reflect on their own opinions and assumptions about what old age is or should be like.

Whilst most of what has been discussed here is the subtler side of ageism, there is of course a real risk of explicit ageist discrimination limiting opportunities to work or participate in society, or for people to find that they are spoken over or patronised due to others' assumptions about their age. As one consultation respondent put it, "staff talking to elderly residents as if they are small children rather than intelligent adults who just happen to be a bit older is one of my bugbears. It happens far too often. I tell them frequently that I may be old but that doesn't mean I'm stupid."

The Equality and Rights Programme does not currently incorporate any work on ageism. This needs to be addressed.

## 5.2. Culture of Care Provision

**Recommendation 5b): To direct the Policy and Resources Committee to monitor and support initiatives within Guernsey and Alderney that engender a positive, enabling, and person-centred attitude towards the delivery of support and care.**

To have good care and support is not just about having the right quantity of provision, it is also about quality and about how care recipients or care providers think about care and support.

There is a risk that care and support is thought about as something which is designed to keep someone fed, safe and warm but nothing else; or we think of care and support as something which the care-giver is magnanimous to offer and that doing something for someone is always what they need or want. However, this mind-set may prevent people from doing what they are able to, encourage others to do things for individuals rather than supporting them to do something for themselves or doing things with them, or may fail to support individuals to lead lives which are meaningful to them.

The Disability and Inclusion Strategy (2013) was based on the Social Model of Disability:

*"The social model of disability identifies systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) that mean society is the main contributory factor in disabling people i.e. it is the society as a whole that is responsible for creating barriers to full participation of persons with disabilities, and it is the society as a whole that has the responsibility to remove them." (Delia Ferri, 2011)*

<sup>51</sup> Angus, J. and Reeve, P. (2006) "Ageism: A Threat to "Ageing Well" in the 21<sup>st</sup> Century", *The Journal of Applied Gerontology*, 25(2), pp. 137-152.

For this Strategy also, it is essential to develop a model where it is understood that it is society, attitudes, culture, and the way that our social institutions, events and built environment are designed exclude some people and prevent them from functioning and realising their potential. This is in contrast to a medical model of disability: where the disability is related to a diagnosis of an impairment or condition and it is this impairment or condition which makes people incapable of functioning socially or economically. The medical model, therefore, places a focus on 'fixing' the individual rather than their environment. It focuses on what a person cannot do compared with a 'normal' person, rather than focusing on what they can do.

It is important for the Strategy that we focus on empowering individuals by developing their environments and challenging social attitudes, and not focusing on "fixing" individuals. Under the social model of disability it is important to aim to remove barriers to social inclusion and encourage participation, rather than segregate individuals because of their condition. It is also important to ensure that individuals are listened to, respected, and included in decision making, and not treated paternalistically. Without the proper housing, adaptations, equipment, or support, people will not be able to participate in society.

Following the lead from the Disability and Inclusion Strategy (2013), there is a need to ensure that care and support is provided to enable people to live in a way which is meaningful and fulfilling, and not in a way which is patronising or disabling.

The SLAWS consultation found that when asked '*How often do you feel that your views are included in decisions made about your care and support?*', 64% responded never, rarely or sometimes. 43% of respondents felt that care staff tended to do things for people rather than supporting people to do what they were able to do. There is, therefore, a need to work towards a situation in which people's views are always included in decisions made about their care and support, and where care staff always support people to do what they are able rather than doing things for them.

Some people who were previously residents in HSSD's Learning Disability Accommodation service are now resident in the extra care housing. This has had a significant impact on enabling people to do what they are able to: one resident said "I still see the staff who supported me in the residential home but only for occasional social outings and the odd health appointment now as I don't need them to do things for me anymore. I am able to do so much more for myself now I have my own space!"

There has been some successful work undertaken relating to the culture of care provision within HSSD's Learning Disability Service. The Positive Behaviour Support Team launched an 'Active Support' initiative:

The core components of Active Support are:

- Providing 'real' activities at home and in the community
- Organisation of support to maximise involvement
- Training to develop an enabling style of support
- Monitoring of improvements in practice

Active support is underpinned by a strong social values base. At the heart of the approach is a belief in people's right to have choice and control in their lives, independence, respect, and social inclusion, regardless of their level of disability. Active Support helps to put these values into practice, by enabling people to participate in activities that are meaningful to them, and also valued by society.

Active Support has been proven to increase service user's involvement in activities, and the quality of support that staff provide. Interestingly, services in the UK have successfully implemented Active Support without any increase in staffing. This suggests that it can be a resource efficient way to deliver more effective support.

A total of 54 staff from four community homes in Guernsey were trained to use Active Support techniques. Data was collected before and after the training, to see whether it had an impact on the amount of time that service users spent doing meaningful activities. Information about staff's support style was also collected, to see whether the training had any impact on their ability to build positive relationships with service users.

The results of the project showed a range of positive outcomes. Following the training, service users spent approximately 15% more time engaged in meaningful activities. Staff were twice as likely to provide service users with assistance to do the activities, and they were also shown to have 'warmer' and more positive relationships with the people that they supported.<sup>52</sup>

Further work needs to be undertaken into how we think about and provide care and support across all need groups and care settings. This work is not about staffing numbers but the qualitative day-to-day interactions between existing staff and the people that they support.

### 5.3. Loneliness

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**Recommendation 5c): To direct the Policy and Resources Committee to investigate the issue of loneliness in Guernsey and Alderney, reporting to the States with its findings and any recommendations no later than February 2019;**

Loneliness is subjective. Different people will experience different kinds of loneliness for different reasons. Addressing loneliness is about supporting people to have the quality and quantity of social relationships in their life that they wish to have and to ensure that they have someone to turn to when they need support.

Loneliness is a key issue for social care policy. Increasingly, loneliness is recognized as a public health issue for the following reasons<sup>53</sup>:

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<sup>52</sup> *The Changing Times – Social Policy Newsletter, Issue 2, August 2015*, Available at: <http://www.gov.gg/socialpolicynewsletter>.

<sup>53</sup> (Campaign to End Loneliness, 2015).

- Loneliness can have a similar health effect to cigarette smoking and is a greater risk factor to health than obesity<sup>54</sup>;
- Lonely individuals are more likely to visit their GP and use more medication<sup>55</sup>;
- Loneliness increases the chance of developing long-term care needs and the chance of entering residential and nursing care sooner<sup>56</sup>;
- Lonely individuals are more likely to develop depression<sup>57</sup>;
- Loneliness is linked to an increased likelihood of cognitive decline<sup>58</sup>; and
- Lonely individuals are more likely to call on emergency services<sup>59</sup>.

The fact that loneliness is so significant in maintaining health and wellbeing suggests that seeking to address loneliness within the Islands could significantly prevent the rate of increase of long-term care costs by helping to improve individuals' well-being, and reducing the likelihood of them seeking a placement in a formal care setting.

A range of community-based initiatives have been explored in the UK to attempt to address loneliness. All communities are different. Any initiative pursued in Guernsey or Alderney needs to be tailored to the Island's needs and the social opportunities that Islanders are seeking. Successful initiatives from the UK could provide a starting point for considering what would work in Guernsey. This could include, for example, befriending schemes (which were suggested by some respondents to the consultation), but goes much further than that: the work undertaken needs to identify what social opportunities people want, whether these opportunities exist, and what barriers there are to accessing these opportunities – building upon and facilitating access to the existing social networks and social life of the Islands for those who are at risk of isolation.

The States cannot pursue these kinds of initiatives alone. By working with the third sector it should be possible to facilitate the development of community-based approaches to tackling loneliness; this needs to be in accord with evidence-based practice and could be usefully supported by Public Health initiatives.

In the meantime, existing initiatives should be acknowledged. The Silver Line, a UK based, free, 24 hour, confidential helpline for older people was launched in Guernsey in 2013. It was reported in September that, since the launch, 4,257 calls had been received from the Channel

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<sup>54</sup> Holt-Lunstad J, TB, Layton JB. 2010. Social relationships and mortality risk: a meta-analytic review. *PLoS Medicine* 7 (7)

<http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000316>.

<sup>55</sup> Cohen, G.D. et al. 2006 'The impact of professionally conducted cultural programs on the physical health, mental health, and social functioning of older adults' *The Gerontologist* 46 (6) <http://gerontologist.oxfordjournals.org/content/46/6/726>.

<sup>56</sup> Russell DW, Cutrona CE, de la Mora A, Wallace RB. 1997. Loneliness and nursing home admission among rural older adults. *Psychology and Aging* 12(4) pp.574-89.

<sup>57</sup> Cacioppo JT, Hughes ME, Waite LJ, Hawkley LC, Thisted RA. 2006. Loneliness as a specific risk factor for depressive symptoms: cross-sectional and longitudinal analyses. *Psychology and Aging* 21 (1) pp. 140-51. <http://www.ncbi.nlm.nih.gov/pubmed/16594799>.

<sup>58</sup> James BD, Wilson RS, Barnes LL, Bennett DA. 2011. Late-life social activity and cognitive decline in old age. *Journal of the International Neuropsychological Society* 17 (6) pp. 998-1005. <http://www.ncbi.nlm.nih.gov/pubmed/22040898>.

<sup>59</sup> Geller, J.; Janson P, Mc Govern E, and Valdin A (1999) Loneliness as a predictor of hospital emergency department use. *Journal of Family Practice*, 48(12): 1002.

Islands: per head of the population over 65 this represents double the rate of call from the next highest region<sup>60</sup>. Autism Guernsey and MENCAP have been operating a Befriending scheme which provides one to one support to adults with a learning disability and/or autism via a trained befriender. The scheme was launched in May 2013 with four recruitment drives so far. 74 referrals have been received in total with 22 people waiting for a befriender. 43 befriender matches have been found. The uptake of these initiatives indicates that there is demand for services related to loneliness and inclusion and members of the community are likely to value further development in these areas.

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<sup>60</sup> Information provided to us by The Silver Line. Also reported in ITV News (2015) Concerns for lonely OAP's in the Channel Islands, *ITV News*, 17<sup>th</sup> September 2015  
<http://www.itv.com/news/channel/story/2015-09-17/elderly-people-twice-as-likely-to-get-help-for-loneliness-in-channel-islands/>  
 N.B. there may be a number of factors, other than levels of loneliness, which might affect call volumes including for example, publicity around the launch of the line.

## Section 6: Service Development Priorities

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In Guernsey and Alderney at present we have a wide range of services for people with enduring care and support needs, as outlined in section 2 above. Changes are already being made in many areas to improve services, and there is good practice and innovation happening in the Islands today being led by the dedicated staff and managers who work in those services. Work is already being progressed which will further the Strategy both within Departments and as part of the Mental Health and Wellbeing Strategy and Disability and Inclusion Strategy (some examples are highlighted in this section).

Nevertheless, from a strategic, 'big picture' perspective, changes need to be made to the whole system to **aim to align service structure with the priority outcomes outlined in section 1.4**. This will require finding ways to:

- improve the manner in which different organisations work together to deliver services (as also described in section 3);
- identify gaps in service provision and how they can be met;
- identify those services that are no longer meeting the needs of adults with long-term care and support needs, and which need to be reconfigured; and
- build on existing good practice.

Building on Phillips' (2014) vision for the future of the health and social care system, the Working Party believes that the system should provide seamless, joined-up support for those who need it including:

- Clear places to go for **information and advice**. Much of the feedback we have received has highlighted that people are often not sure of what is available and are not clear about where to go for help. This requires both that better information, advice and coordination of care is provided, but also that where individuals have interactions with specific services there is effective signposting of service users to other areas of support where possible.
- In addition to Primary Care services, **the local community** themselves must be an integral part of the foundation for a new system of care and support. As well as the important role of carers, and community and not-for-profit organisations, the support which individual Islanders can provide in their day-to-day encounters on the bus, in shops and in their local neighbourhoods is important in making the Island a better place to live (see for example, work in the UK on Dementia Friendly Communities, which some community organisations are exploring bringing to Guernsey)<sup>61</sup>.
- **Mental health services should be more integrated** with physical health so that people needing support from both services receive coherent support.
- Services should be **person-centred**. This means that there should be a range of services available which can be tailored to meet individual needs. There should be continuity to service provision, and the system should be integrated so that the

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<sup>61</sup> e.g. alzscot.org/dementia\_friendly\_communities.



individual experiences a coordinated and seamless service that meets their needs (as described in the care continuum section 2.2.2 above); and that they are clear about where to go for help with managing their care when their needs change.

- **Carers should be recognised** and supported throughout the care system. Carers are part of the care provision picture and should be worked with in partnership. It is necessary to recognise that without carers, considerably more care and support would be required from the States.
- People should be supported as they move through different services and different phases of their lives. There should be **continuity** when someone with long-term needs moves into or out of hospital. There should be continuity and support when someone approaches the end of their lives.

A substantial, ongoing programme of change will be needed to improve services. It is not possible to outline all change within this report. Rather, this section describes **priorities for change** identified through the research work undertaken to date, and supported by the concerns raised in the public consultation.

The discussion is split into eight key sections:

- 6.1 Support for carers
- 6.2 Coordination, information and advice
- 6.3 Community Services and re-ablement
- 6.4 Specialist housing and care homes
- 6.5 Addressing specific conditions
- 6.6 Eligibility
- 6.7 Health Promotion
- 6.8 Other service needs

## 6.1 Support for Carers

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### 6.1.1 Support for informal carers

**Recommendation 6(a): To direct the Policy and Resources Committee, in conjunction with the Committees for Health and Social Care and Employment and Social Security, and appropriate third sector organisations, to develop, as a matter of priority, a Carers Strategy and to report to the States with its recommendations no later than June 2018.**

#### a) *Who are carers?*

When an adult has care and support needs it is often their immediate family or closest friends who help them. Carers may be family members, including children and young people, who live with the person they care for, or family, friends or neighbours who live elsewhere. The people

who care for their family or friend are referred to as ‘informal carers’, or just ‘carers’. Current estimates suggest that there are between 2,000 and 4,000 carers in Guernsey<sup>62</sup>.

Carers may help with tasks such as getting up and going to bed, washing, dressing, using the toilet, shopping, cleaning, laundry and making meals. Providing care may mean keeping an eye on people who are confused or at risk if they are not supervised, or encouraging them to do everyday things for themselves.

b) *Link to other strategies*

The needs of carers have been recognised in previous strategies, where the situation of carers was raised as an area of concern, and the onus remains on this Strategy to address their needs. For example, the Disability and Inclusion Strategy<sup>63</sup> noted that:

*“It can be the case that a carer’s needs are forgotten, or are assumed to be the same as the needs of the person they care for. In reality, carers have their own unique needs, including the need for emotional and practical support, enabling them to maintain their own physical and mental health and wellbeing. Some carers will be able to support a very disabled person who is dependent on them for many years, more or less alone. Others will struggle to support a much more independent person. A carer’s strengths and weaknesses have very little to do with the condition of the person they are supporting, and it is important that there is support for carers, in turn, which recognises this.*

*Carers are at risk of becoming isolated from their own natural support network – family, friends, colleagues, and so on – the more time they spend caring. This is as true for people with a family member in an off-Island placement, who spend large amounts of time travelling to and fro in order to be with them, as it is for people who are with the person they care for every day.*

*Caring for another person is one of the most valuable – and least valued – roles in society. If a carer is also working full or part time – as many carers are – he/she is making a significant contribution to the economy, but may require flexibility or a change in hours to accommodate both roles. It is important to ensure disability equality legislation, information and other provisions would include carers as a separate strategy has not been developed for them.*

*There are also a number of children who care for disabled family members. The local research identified a very small number of people aged 16-34 who say their primary*

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<sup>62</sup> The Disability Needs Survey estimated 8% of households (2085 households) contained carers in 2012 (<http://www.gov.gg/disabilitystrategy>). In 2014 the Guernsey Healthy Lifestyle Survey (<http://www.cph.org.uk/wp-content/uploads/2015/01/Guernsey-Healthy-Lifestyle-Report-2014-12th-December-Final.pdf>) estimated 5.7% of participants had caring responsibilities (expanded to the whole population this would mean 3,576 people); in 2011 the Housing Needs Survey estimated 15% of households contained people with caring responsibilities – 3,847 households (<http://www.gov.gg/CHttpHandler.ashx?id=79858&p=0>). Confirming an exact figure is complicated by the fact that many people who care do not define themselves as ‘carers’, and might see their role as a normal part of family life.

<sup>63</sup> Policy Council – ‘Disability and Inclusion Strategy’ – Billet d’État XXII 2013.

*source of care and support is their child – who, because of the age of the parent, is therefore likely to be a young carer. Not a lot is known about children who are carers, but this is something that Health Information Guernsey began to address through a child carers project, and which was identified as a priority through the first Children and Young People's Plan.*

*Assessments for community care services and for respite care do take into account the needs of the carer, but these are not the primary focus, and there is no support put in place purely for the carer.*

*It is important to ensure, in future, that the needs of carers are taken into account when assessing a disabled person's support needs. The Supported Living and Ageing Well Strategy therefore needs to include provisions for carers as well as disabled people.*

*The development of improved information services, both in general and at specific transition points, will also help carers to be more prepared for the future and to access the support that they, and the person they care for, need, when they need it."*

The Mental Health and Wellbeing Strategy also acknowledged the need for Carers to be supported. It defined carers as people who informally care for someone with mental illness, e.g. family, neighbours and friends.

One of the cross-cutting themes of the Mental Health and Wellbeing Strategy<sup>64</sup> was **"addressing the needs of carers"**. The research report supporting the Strategy provided the following quote:

*"Long-term carers are at particular risk of mental ill health. Proactive help for carers, particularly when the cared-for person dies or enters residential care, can help prevent them feeling emotionally and socially adrift (Milne, 2009)."*

The research report further expanded on this with the following section on carers and relatives:

*"The experience of a family member having a mental health problem can have a significant impact on carers. In recent years this has been acknowledged, and there is a growing expectation that carers are involved in care planning and their needs are assessed as part of this process."*

The latest revision of the Children and Young Peoples' Plan has also identified young carers as among those children and young people with vulnerabilities.

There is an expectation from all of these strategies that SLAWS will lead on taking action to address the need for support of carers.

The Domestic Abuse Strategy<sup>65</sup> also links to caring – sadly, in some cases the relationship between a carer and the person that they care for is, or becomes, abusive. Ensuring that there

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<sup>64</sup> Billet d'État III, February 2013.

is adequate support in place for people within this situation is important and needs to be addressed through both this Strategy and the Domestic Abuse Strategy.

c) *Evidence and policy context*

Informal carers are increasingly recognised through national policies in other jurisdictions. Guernsey stands out at present for being the only member of the British Irish Council not to have a Carers' Strategy.

There is increasing recognition of the economic and social contribution of informal carers. In 2011 Carers UK estimated that carers in the UK made an economic contribution of £119bn. per year<sup>66</sup> – that is, if those carers did not undertake the care work that they did, the government would need to find replacement care to the value of £119bn. An initial estimate for Guernsey is that the replacement cost of informal care would be £29m per annum, but this is a conservative estimate and the reality may well be higher.

In addition, it has been recognised that there are unseen costs in not supporting carers<sup>67</sup>:

- As noted above, carers are at risk of damaging their own health and mental wellbeing through caring intensively, which has quality of life implications and can also create increased long-term health and social care costs. If this Strategy is intending to prevent avoidable deterioration in health and wellbeing, support for carers needs to be recognised as part of that picture.
- Carer breakdown can lead to early admission to expensive intensive forms of care for those who are receiving care, but may also lead to the carer developing care requirements themselves.
- Caring can significantly impact the career and career prospects of carers; either through changing hours, not accepting promotions, changing job, or in some cases giving up working.
- Caring can remove skills and talents from the workforce leading to lost economic opportunity.
- Carers are at risk of financial hardship and social exclusion.

All of these factors suggest that it is appropriate for the States to take a strong interest in supporting carers to undertake their caring roles and to combine this with a wider life and employment if their situation permits.

Ensuring support is available to carers is even more important, because significant social changes are underway that may affect the availability of informal care in future:

- *Family structures are changing* – people are having fewer children and divorce rates are relatively high. Alongside this, people's expectation of family relationships and the degree of responsibility for providing care to family members is changing.

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<sup>65</sup> Billet d'État XXIII, December 2015.

<sup>66</sup> <https://www.carersuk.org/news-and-campaigns/press-releases/unpaid-carers-save-119-billion-a-year>.

<sup>67</sup> For an overview of evidence see Carers UK (2014) *Facts about carers*, available at: <https://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2014>.

- *Gender roles are changing* — it is the expectation now that all working age adults will work, rather than having a (male) family breadwinner. This means that there are likely to be more people trying to combine work and care.
- *People are increasingly dispersed* – there may be an increased number of older and disabled adults in future who do not have family living on the Islands.
- *Generational changes* – current and future generations may have different attitudes towards an expectation of care giving than previous generations.

**The Working Party acknowledges that given the demographic and family challenges ahead, there has never been a more important time to focus resources on ensuring that informal carers themselves feel supported to continue their caring role.**

d) *The consultation*

As part of the public consultation, there was considerable feedback suggesting that carers currently felt unsupported in their caring roles.

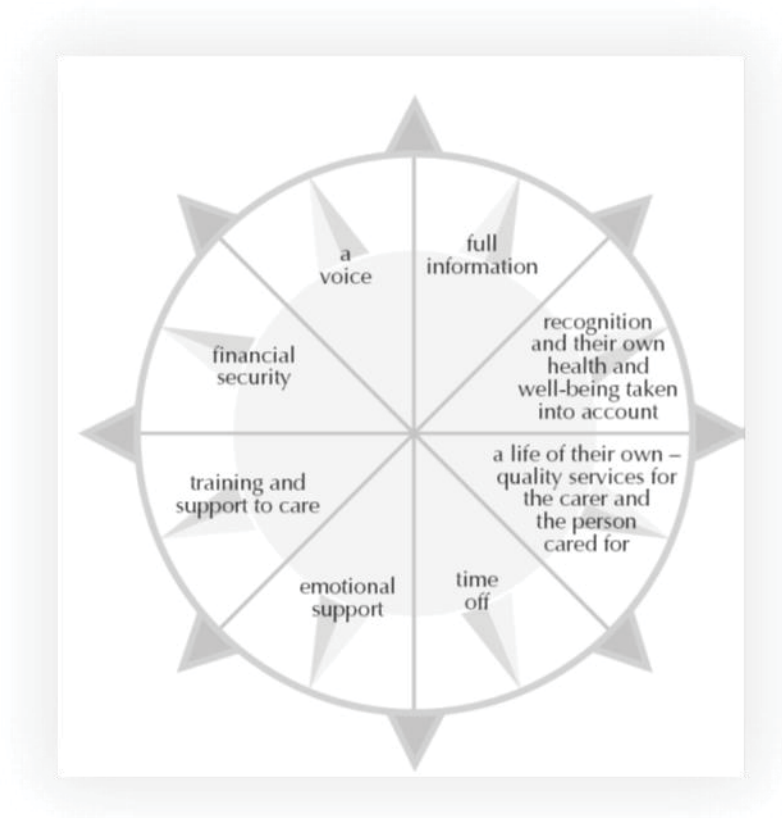
Previous to the consultation, Phillips’ report for the Working Party highlighted, as a ‘service gap’, that there was a need for third sector organisations to provide support for carers: “... there is a Carers Association in Guernsey [Carers Coming Together] but it is very small and has limited capacity”. She also noted the lack of training, information and advice, and short-break services, each of which were discussed in the consultation.

Phillips suggested developing a Carer’s Strategy along the lines of the Southwestern Sydney Local Health District “Carers Compass”<sup>68</sup> see **figure 6A** below.

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<sup>68</sup> Health Department South Western Sydney Local Health District, Australia, “Model of Care for Carers: Carers’ Compass & Checklist” Available at: <http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB4QFjAA&url=http%3A%2F%2Fwww.swslhd.nsw.gov.au%2FCarers%2Fcontent%2Fpdf%2FCompassModelofCare.pdf&ei=ymKNVcPxGung7Qa9vbe4DQ&usg=AFQjCNFH9xKyxzJNevCYTUp1YPHVYojWQw&bvm=bv.96782255,d.ZGU>.

Figure 6A – the Carers' Compass



The consultation document (question 21) asked for people to express their views about how important a number of priorities were for carers. Although there were some technical difficulties with the responses, which necessitated analysing the results by looking at weighted data sets<sup>69</sup>, the following five areas of support were noted as the most important forms of support for carers:

- Respite care;
- A carer's assessment, which would identify the support carers need to continue caring;
- More general support\*;
- Training and advice about the care and support needs of the person they care for; and
- Information and advice for carers on services and other forms of help available.

\* There were some comments on lack of clarity about what 'more general support' meant.

<sup>69</sup> A full description of the responses to question 21 is provided in Appendix D.

When asked (question 22) ***'Is there a priority for carers that we have not covered above?'*** the suggestions of priorities from respondents included:

- Peer support from other carers;
- Reliable respite care that can be pre-booked;
- Risk assessments for carers supporting people with cognitive disorders;
- More general training for carers, including emotional wellbeing and manual handling;
- Counselling for carers;
- Having a contact to check on them and who they can call when they need support;
- Help filling in forms and legal documents;
- Targeted help for young carers;
- It was suggested that assessments and offers of help should be undertaken as a matter of course, rather than waiting for an individual to ask for an assessment or help;
- Financial support for those who cannot access carers' allowance;
- Day centres;
- Support carers to maintain their independence; and
- Personal budgets for carers.

*e) What is already happening?*

We do not have a Carers' Strategy; however, some work is already underway to support carers. For example:

- The Disability and Inclusion Strategy (2013) initiated a workstream to introduce legislation to address discrimination against disabled people and their carers. This should support carers who face discrimination in work and other settings because of their caring role.
- HSSD have been offering 'carers assessments' to those who come into contact with Community Services in order to assess the situation and needs of both the carer and the person being cared for.
- Carer's Allowance was reformed in 2014 to remove the limit on the number of hours worked, meaning that any carer that cared for 35 hours or more per week could claim Carer's Allowance regardless of whether they combined this with paid work or not.
- The Older Adult Mental Health Community Team has been offering information sessions for carers of people with dementia.

*f) What will we do?*

The Working Party recommends that a Carers' Strategy should be developed to identify ways to better support carers in their roles and to understand their needs. A Carers' Strategy should consider all of the social and economic implications of caring and ensure that carers have support to enable them to:

- be equipped with the skills, knowledge and information required to perform their caring role;
- retain their ability to participate in society and maintain their own health and wellbeing (carers may need support or additional help to enable this); and



- remain working or to re-enter employment, as caring often reduces a carer's ability to work and earn a living.

The Carers' Strategy will also help to communicate who carers are and what support can be offered to them. Given the importance of informal carers as part of the social care system, the Working Party considers that this should be a priority. The Working Party also considers that, as part of its development, it is essential to work closely with carers and with third sector, e.g. Ageing Well in the Bailiwick and the Guernsey Disability Alliance.

#### 6.1.2 Short break services (previously termed respite care)

**Recommendation 6(b): To direct the Committees for Health and Social Care and Employment and Social Security to review and address, as a matter of priority, the range, provision and funding of short break services for both persons with long-term care needs and their carers, and to report to the Policy and Resources Committee no later than the end of 2017 with a business case for the development and realignment of short break services, in the light of their findings.**

There are currently several types of short break services available in Guernsey to provide temporary care arrangements for those who are usually primarily supported by an informal carer. This can both enable those individuals with care or support needs to spend time with people, be in places or undertake activities that would not otherwise be available to them, and can also enable those who care for others to have a break from caring.

*a) What is currently available and recent developments*

*Bed based services:*

The following short break beds are available:

- 2 flats in the GHA extra-care schemes. These are available to all adults who need them (though they may not be suitable for adults with very complex needs). They are funded by HSSD.
- 1 flat is available at Rosaire Court extra-care scheme (primarily for over 55s). It is funded by HSSD.
- 2 beds at the Duchess of Kent, which are for older adults with mental health conditions or dementia.
- 2 beds on the Lighthouse Wards, which are for complex physical needs.
- 1 bed at Summerland Nursing Home, which is more suitable for Older Adults with nursing needs but could be used for anyone, and 1 bed in a private residential care home<sup>70</sup>. These are funded by HSSD.
- The Guernsey Cheshire Home has 1 bed, which is for nursing care status for adults with physical disabilities and complex needs.
- 2 beds at Beauville – a community home for people with learning disabilities – are reserved for short breaks.

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<sup>70</sup> HSSD currently pay a full-rate for these beds all year around to keep the beds open for respite services.

- Other residential and nursing homes do take people for short breaks, but this tends to be on an ad hoc basis when they have capacity.

In order to access bed-based services a Needs Assessment Panel certificate is required, for which an assessment is necessary and a Panel meeting needs to be held – accessing short-break services at short notice is, therefore, difficult (though it can be possible through the issue of retrospective certificates where there is clear and urgent need). Whilst some of the beds which are controlled by HSSD are easy to book in advance, where a placement is in a private residential or nursing home, it can be hard to predict where or when a placement might be open which can cause some uncertainty. If a permanent resident can be found to take a bed, this provides a more reliable income for the home than maintaining a short-break bed would, so short-break placements tend to only become available where there is a break between permanent residents of that placement. When these breaks will be cannot often be planned. In recognition of demand and the need for planned short-break services, HSSD have this year begun paying for a bed in a private residential home to expand the availability of planned short-break provision.

*Community-based services:*

Some services have been developed by the Community Health and Well-being Service where a person is supported in their own home rather than in a residential setting. However, this is not currently resourced to support people who need overnight care.

Following the decision to separate the adults and childrens respite provision at the Croft a menu of short-break options for carers of people with learning disabilities was developed. This was designed around the needs of carers rather than around the physical availability of beds and includes a service where staff stay with the person with support needs in their house whilst their regular carer is away. There has been positive feedback from those who have used the service.

There is also a sitting service where a few hours can be offered for someone to spend time with an individual; however, this is easier to arrange for a regular period of time each week than for one-off sessions as and when they are needed. It is not always possible to access a sitting service at short notice.

*Day services:*

There are day services available for some specific user groups including frail older people, people with dementia, and people with learning disabilities.

*Emergency cover:*

Some emergency cover is available. There is a rapid response team who can step in if a carer is unwell, for example. The Learning Disability Service also have an on-call service for emergency cover.

*b) Concerns about short break service availability and range of services*

There has been a long-standing concern about the availability of short break services. A report was produced by Island Analysis on respite care in 2010, funded by the Guernsey Disability Alliance and the MS Society. It noted that respite “provision is lacking or non-existent in some cases”.

The report highlighted a number of issues with services including that:

- There was 'an urgent need for a review of respite services'.
- There were issues of coordination between providers.
- Accessing advice about what respite care was available was difficult.
- There was a lack of respite care for people with physical disabilities.
- Concerns were raised about the use of the Croft for respite care for adults with Learning Disabilities. In response the Croft has become a service only for Children and Young People, and alternative adult respite services have been offered.
- There was a lack of flexibility in Social Security funding<sup>71</sup>, which can only be used for placements in private residential homes and cannot be used to purchase respite care at home.
- There were some discrepancies about who is and who isn't entitled to services based on whether people are or are not on the Learning Disability Register.
- Services need to be more person-centred.
- Planned, consistent services are needed. (HSSD now has beds in extra care and in a residential care home which it did not have at the time of this report, so there has been some expansion in the capacity of planned short-break services, though this issue was raised again by respondents to the SLAWS consultation.)
- There needs to be a range of respite care services. (There has been some expansion, since the drafting of this report, of respite care services provided to people in their own homes.)

Whilst there have been changes since 2010, there are many outstanding issues and stakeholders have raised concerns with the Working Party about the availability and range of services available throughout the development of the Strategy.

Consultation respondents were particularly concerned about the ease of accessing respite care when needed.

In the consultation we asked - *'To what extent do you think that existing respite care services cater to the needs of the following groups?'.* All groups specified had a majority who felt that there was 'insufficient provision'. The following comments were received:

- Whilst respite care is provided through the Learning Disability Service, respondents were concerned that there is no respite support for individuals who have autism but do not have a learning disability.
- Some felt that the respite care available for individuals with complex needs in the Lighthouse Wards was not appropriate due to its association with individuals with dementia and challenging behaviour.

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<sup>71</sup> Individuals wishing to access short-break services first need to receive a Needs Assessment Panel certificate (as explained in section 2.2.3 above). They can then apply to receive Long-term Care Benefit from the Long-term Care Insurance Scheme if they take a placement in a private or not-for-profit residential or nursing care home. Where Long-term Care Benefit is granted to individuals for short-break purposes, they are not asked to pay any co-payment. It is possible, however, that they may need to pay a 'top-up fee'.

- Some felt that the loss of the community home at the Croft was detrimental for adults with learning disabilities since this had allowed people to socialise with others that they knew, and that individual respite care services were not an adequate substitute.
- It was noted that the only respite care available for people with mental health conditions was at the Albecq Ward and it was felt that this was not ideal.
- There was concern that residential and nursing homes were being used to provide respite care to younger people with care needs and that this was inappropriate.
- There were concerns that respite care was limited in availability, and could be expensive for people with physical disabilities.

***Conclusion***

Despite some recent developments in short-break services, responses from the consultation and the level of concern raised by the public suggest that there remains, as in 2010, 'an urgent need for a review of respite services.' This needs to address matters of scope and availability, and how these services are impacted by their current funding arrangements. This also aligns closely with the development of a Carers' Strategy, as short-break services can play a key role in supporting informal carers.

## 6.2 Coordination, information and advice

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**Recommendation 6(c): To direct the Committee for Health and Social Care to report to the Policy and Resources Committee no later than the end of 2017, with the results of an investigation into the establishment of a proactive care coordination service, providing a single point of contact to those with significant care and support needs to assist them in arranging and coordinating their care and support from public, private and third sector bodies, including signposting to advice on how services are funded and paid for.**

Research undertaken for the development of this Strategy and the Disability and Inclusion Strategy has consistently shown that people have struggled to gain information about, and access to, the services that they need. This can be a particular struggle where there are issues with service coordination, resulting in several different organisations needing to be contacted to arrange or rearrange care arrangements as a person's condition changes.

Concerns have also been raised about the number of professionals that some people see on a routine basis and the fact that no single professional is the key point of contact. When something goes wrong, people may need to contact multiple organisations and professionals. This can be confusing and stressful, and can mean that there is a lack of opportunity to build a key stable and trusted relationship with a professional who has a clear view of the whole of that individual's situation.

Phillips (2014) suggested that GPs should be the first point of contact and the coordinators of care. She argued that they were best placed to know the patient's history and circumstances and to assist with arranging care and regularly reviewing those arrangements.

The Working Party acknowledges the key role of GPs: they must work effectively with the rest of the care and support system to support people in need. However, it is not felt that GPs are necessarily the right people with the right skill set to assist with coordinating care and benefits in a person-centred way. Instead, it is recommended that 'care coordinators' be established to act as single points of contact. It will be necessary for these professionals to have a good understanding of the range of services, support groups and benefits available and to advise on what support can be provided as well as assist in arranging changes in a care package when needed. They will also need to be proactive about connecting the individual with the care services, benefits, and community support that they would benefit from.

This could have a significant positive impact on people's lives. An example case study of the effect of this kind of work is included in Appendix F.

These care coordinators will clearly be assisted by the project being undertaken as part of the Disability and Inclusion Strategy to make information more available and accessible for people with care and support needs and their carers (see section 3 above.)

### 6.3 Community Care Services

**Recommendation 6(d): To direct the Committee for Health and Social Care to investigate, as a matter of priority, the expansion of the range and availability of community care services, including but not limited to:**

- **the expansion of services for rehabilitation and re-ablement for those recovering from hospitalisation;**
- **the establishment of short-term care in the community to provide an intermediate level of support between hospital and living at home;**

**and to report to the Policy and Resources Committee no later than the end of 2017 with the relevant business case(s), in the light of their findings.**

The report in which the States agreed the introduction of the Long-term Care Insurance Scheme report in 2001 highlighted that:

*To guard against the creation of a perverse incentive to go into institutional care, it is important to ensure that the Board of Health's community care services are maintained at a satisfactory level. A current shortfall has been identified and plans have been made to enhance a wide range of services<sup>72</sup>.*

Whilst some expansion and improvements have been made with good effect – including for example, the development of the Rapid Response Service - the full intended range of enhancements were not achieved<sup>73</sup> and community services remain under-developed to this day. Combined with poor information provision, Islanders may well be less aware of what Community Services there are and what they do, which reinforces the historic reliance on residential homes as the service of choice when significant care and support needs arise. The consequence can be that more individuals move into more costly, high-dependency care settings earlier than necessary.

*a) Concerns about the existing availability and range of services*

Through Phillips' work and the public consultation undertaken, the Working Party is aware of the following concerns about existing services:

- Some individuals expressed a preference for being able to choose to receive services at home rather than move into a care home.
- There are concerns about the lack of availability of services, particularly at peak times and weekends. As a consequence:
  - Some respondents reported having no control, or certainty, over what time they would be visited by a member of the Community Services team. This

<sup>72</sup> Billet d'État III, February 2001.

<sup>73</sup> For example, the laundry service, the additional staff for the night sitting service and some of the other initiatives mentioned in Billet d'État III, February 2001 para. 73 were never implemented due to the fact that they were not prioritised for funding or expansion was influenced by the Staff Number Limitation Policy.

- could, for example, mean having no option other than to get up at 10am and go to bed at 7pm when the hours preferred are significantly different.
- Some people find that Community Services are not always available when needed. 77% of respondents replied that they sometimes or often had difficulty accessing Community Services when needed.
- There were sometimes waiting lists for services, or to see a particular kind of professional (e.g. a social worker or occupational therapist).
- Services such as physiotherapy do not follow people out of hospital into the community, which means a loss of continuity and a drop off in support when people leave hospital.

In order to increase the availability and range of community care services, the Working Party believes a dual approach is necessary. First, by expanding the coverage of the Long-term Care Insurance Scheme so that benefits are payable to enable people to purchase domiciliary care services (see section 7), which would encourage the development of community-based services in the private and third sectors. Secondly, by examining the way in which HSSD's community care services are developed and deployed. In relation to this second point, the Working Party supports work underway in HSSD to develop 're-ablement services'. The remainder of this section focuses on developing the range of services available within HSSD's community care services.

*b) Concerns about the provision of a range of enabling community care services*

As Melinda Phillips explained:

*"Traditionally the system in Guernsey and most advanced economies has been based on hospital treatment of illnesses as they arise. If the illness persisted the patient would either stay in hospital or move into [institutional] long-term care. However, technology, better diets and healthier lifestyles have meant that we are living longer, often managing long-term conditions for several years..."*

*All systems are struggling to shift the balance from hospitals and care homes to self-management in one's own home for as long as possible with the right support. This in turn requires services to be delivered differently so that they are focused on the person's needs and delivered in a co-ordinated way."*

At present there is a risk that services are too hospital based and do not support people to self-manage their conditions. There is a need for balance:

- on the one hand there is a risk that insufficient resources and support are provided to allow someone to live in a meaningful way, participate in society or obtain the therapy or tools that they need to be able to care for themselves.
- but on the other hand there is a risk of over-providing services in such a way that encourages people to rely or depend on staff to do things which they could do for themselves (linked to care culture, discussed in section 5.2 above).



It is important that we ensure that services find this balance and support people in the community to gain and maintain the skills that they need to self-care.

Services also need to be smarter about the interplay between health services and social care services, particularly in crisis situations. This needs to be both to prevent people from entering hospital when they do not need to and can be supported in the community, and also to help people to recover after they have been in hospital.

We already have a 'rapid response team' which can provide a package of care to someone who has become ill in order to prevent their condition from worsening or to prevent them from needing to be admitted to hospital. It would be possible to expand on this provision. NHS trusts in the UK have attempted to provide support to people at home via community services when someone has a fall, for example, by mobilising health professionals where previously that level of service could only have been provided in a hospital<sup>74</sup>. Medical treatment is brought to the person in the community and they are supported to recover at home.

Services are also needed to help people to recover when they have experienced a health crisis or have been admitted to hospital. This entails the development of a re-ablement programme.

### 6.3.1 Re-ablement

Re-ablement services focus on enabling individuals to return to live as independently as possible in the community after an acute episode of illness, an accident, or the development of a long-term condition. Re-ablement can also be important in circumstances where an individual has been supported by a family member or professional carer and has become used to having things done for them and, due to a change in circumstances, needs to learn or re-learn the skills that they need to self-care.

Re-ablement is intended to focus on enabling the individual to be as independent as possible via a short period of intensive therapy support.

There are a variety of different re-ablement delivery models and an extensive evaluation literature that confirms an enduring, positive impact (i.e. upon the completion of a re-ablement service, users need less/no health and social care support). A 2007 study for the Department of Health's care services efficiency delivery network, for instance, found that up to 68% of people no longer needed a home care package after a period of re-ablement, and up to 48% continued not to need home care two years later<sup>75</sup>.

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<sup>74</sup> NHS Worcestershire, Well Connected programme <http://wellconnectedworcestershire.co.uk/>. Other important work is underway with the *Commission on Improving Urgent Care for Older People* due to report back in January 2016.

<sup>75</sup> Department of Health (2007) "Homecare Re-ablement; Efficiency Delivery: supporting sustainable transformation: Retrospective Longitudinal Study" Available at: [http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAAahUKEwi4v56jueXIAhWB2RoKHWP RDHs&url=http%3A%2F%2Fwebarchive.nationalarchives.gov.uk%2F20120907090129%2Fhttp%3A%2Fwww.csed.dh.gov.uk%2F\\_library%2FResources%2FCSED%2FCSEDProduct%2FLongit\\_Study\\_Final\\_Version\\_NEW\\_FORMAT\\_.pdf&usg=AFQjCNFfcsJep6Yh21KJPTo-N-Bh8r8lcg](http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAAahUKEwi4v56jueXIAhWB2RoKHWP RDHs&url=http%3A%2F%2Fwebarchive.nationalarchives.gov.uk%2F20120907090129%2Fhttp%3A%2Fwww.csed.dh.gov.uk%2F_library%2FResources%2FCSED%2FCSEDProduct%2FLongit_Study_Final_Version_NEW_FORMAT_.pdf&usg=AFQjCNFfcsJep6Yh21KJPTo-N-Bh8r8lcg)

Re-ablement services are delivered in people's homes and/or in residential or extra care housing settings. No matter the setting, however, the service is the same: professionals work alongside the patient/user in showing them how to undertake the daily tasks of living. Occupational therapists, because of their unique skills, invariably lead the development of re-ablement services – and home care staff are trained by occupational therapists in the delivery of individual re-ablement programmes. This needs to be supported by the effective and timely supply of aids and equipment (see below).

Re-ablement can also include the development of some bed-based intermediate care. Intermediate care is care provided to someone when they are at a stage of recovery where they still need health care and support at a level greater than would ordinarily be provided at home, but not at an intensive hospital level.

At present when someone continues to need care whilst they recover, but where there is no clinical reason for them to be in hospital, it is not possible for them to continue to receive the support they need in a residential setting outside of hospital. If a bed-based care setting (i.e. a facility within a care home or extra care housing) were available where recovery was possible this could allow people to leave hospital faster and continue to receive a high level of therapy and support. This would both reduce pressure on hospital beds and provide better opportunities for rehabilitation and re-ablement for the individual in question.

There is also concern that individuals using hospital services, but unable to immediately transition to their homes, are, under the current system, placed in residential or nursing care homes but not supported to regain their independence when they would be capable of substantially recovering with the right support. In these cases, individuals unnecessarily remain in care homes, sometimes for many years, which will cost substantially more than providing short-term rehabilitation and support to transition back into their own home. This could be avoided if there could be bed-based provision to use as a stepping stone back home.

The extra care housing service undertook a re-ablement programme for the previous residents of Maison Maritainne and Longue Rue House who moved into the new extra care housing provided on the sites of these two care homes. The re-ablement programme at the developments has had considerable success. Aims for the re-ablement programme included:

- Residents serving themselves at breakfast and tea-time instead of having all meals plated and served by staff
- Residents making cups of tea and preparing light snacks
- Self-medicating
- Showering independently
- Residents doing light housework to keep their rooms clean and tidy
- Residents doing their own laundry and ironing

Changes to the care home service were gradually introduced to provide a platform for the re-ablement programme prior to the closure of the two residential homes. This included changes to the catering model from a full service, staff-centred model to a buffet service at breakfast

and tea-time with a full service lunch. This change in the catering service enabled able bodied care home residents to serve themselves, while those frailer residents received assistance from staff.

It also included the introduction of simple tea stations within the care homes so that those residents, who chose to, could eat breakfast or prepare a sandwich and hot drinks. Domestic services changed to include opportunities for care home residents to do more of their own housework if they were assessed as capable. Medication management within the care homes began to include risk assessments for self-medication so that those residents who were assessed as capable could self-medicate.

Since the closure of the two homes and the opening of the new extra care schemes, the level of care needed by previous care home residents on an ongoing basis has been significantly reduced, so freeing staff time to spend with new tenants of the schemes (See case studies in appendix E). There have also been significant improvements in the level of care required by previous residents of HSSD's residential homes for people with learning disabilities who have moved into the schemes, many of whom have developed a level of independence exceeding expectations.

Work is already underway in HSSD to develop a plan to implement a re-ablement service which will integrate community and hospital services to support people to gain/regain the skills that they need to care for themselves where possible across Guernsey.

### **Summary**

It is vital that we focus on providing community services which meet people's needs, whilst enabling and supporting them to care for themselves where they are able to do so. Services require significant development to provide people with the therapy and support that they might need to become as independent as possible. This should reduce costs in the long-term and reduce pressure on hospital beds. In the meantime, funding structures examined in section 7.5 below will need to be re-examined to determine whether the private and third-sectors can also broaden the range of community services that they provide.

### **6.3.2 Aids, equipment and adaptations**

**Recommendation 6(e): To direct the Committees for Health and Social Care and Employment and Social Security to review the arrangements for the provision, management and funding of aids, equipment and adaptations, and to report to the Policy and Resources Committee no later than the end of 2017 with their findings.**

Throughout the Strategy development, members of the public have raised concerns with the Working Party about difficulties in accessing equipment, aids and adaptations. At present there are three key service areas which are related to aids, equipment and adaptations:

- The **Posture and Mobility Service** (sometimes referred to as 'the Wheelchair Service'), which provides wheelchairs, chairs, and other equipment for individuals with impaired mobility, spinal injuries, and other needs related to their postural support.

- The **Community Services Support Equipment Store**, which loans equipment to users on a temporary basis (up to three months) as requested by professionals in the Community Services team. If a piece of equipment is needed on a long-term basis the individual is expected to purchase the item themselves.
- **Section 10 of the Supplementary Benefit Law**, by which the Social Security Department can provide grants or loans towards the cost of purchasing equipment or adapting properties to make them more accessible to individuals with care and support needs. This is operated on a means-tested basis.

Effective and timely provision of equipment, aids and adaptations is key to ensuring that people are able to live in the community independently and that their physical and mental health does not unnecessarily deteriorate. Whilst someone may be able to use the bathroom, prepare themselves a meal, or go out with the right equipment, without it they may be reliant on an informal carer or community services to help them do any of these things.

At present there are the following issues with equipment provision:

- Confusion over funding mechanisms.
- Lack of procedures for handling, decontaminating, storing, and tracking equipment.
- Requirements for individuals to purchase expensive items of equipment after they have been loaned an item for 3 months, even where they only need the item for another one or two months, with no alternative options around paying to hire equipment.
- Long waiting times for specialist equipment to be ordered and to arrive.

Work is underway to address some of these issues within HSSD. There is a project to review the procedures around equipment management and storage. There has also been a review of the Posture and Mobility Service by the College of Occupational Therapists. HSSD is working with key service user representatives to ensure that all these changes effectively meet the needs of individuals.

Nonetheless, the Working Party considers that these issues merit a specific recommendation to ensure they are tackled.

### 6.3.3 'Telecare'

**Recommendation 6(f): To direct the Committee for Health and Social Care to investigate the introduction of 'telecare' including, if appropriate, commissioning a pilot project to assist with this research, and to report to the Policy and Resources Committee no later than the end of 2017 with its findings.**

'Telecare' is the term for a range of technology that can be used to help to support someone living independently. This can include, for example, pendant or wrist band alarms that can be used to call for help in case of an emergency, such as a fall. It can also include a number of sensors which can alert a carer if, for example, an individual with dementia leaves the house unexpectedly, or leaves the gas or water on. Sensors can also be used to alert carers if someone has an epileptic fit, or can help to remind people to take medication.

Telecare can provide the peace of mind which some people need to continue living independently in the community, and in some cases can reduce the need for more costly care. The popular 'lifeline' system is already widely used in Guernsey and Alderney – where people can have pendant alarm buttons if living at home to call for help if they experience a fall or another emergency – but it would be possible to expand the range of telecare services available across the islands.

A number of pilots of telecare have been run in the UK. The Working Party believes that the potential for success depends on how well a telecare scheme could be adapted to the Guernsey environment, and accordingly recommends that they should be investigated and, if appropriate, piloted as part of such an investigation.

The extra care housing developments have a system of telecare adapted within those communities in which residents have a call button which they can use to call a staff member if need arises. A trained member of the care and support staff will then be able to respond, provide advice, and support the individual to manage their concerns if possible, or where appropriate, call for assistance from a third-party. There is a possibility of expanding this service to offer a wider range of sensors or alarms within the extra care developments, and to expand the system to nearby houses so that individuals in the vicinity with care and support needs can call for support from staff of the extra care scheme. The possibility of expanding the schemes within the extra care developments as pilot projects for further investigation is being explored.

## 6.4 Addressing specific conditions

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Many care and support needs are generic and not related to a condition (for example, if you need some help with shopping the type of service provided might not depend on the nature of your long-term condition). However, some people do need condition-specific support and there are specially tailored services to support them.

The Disability and Inclusion Strategy (Billet d'État XXII, 2013) stated that:

*the research leading up to the Strategy consistently identified four groups of disabled people who face multiple and significant disadvantages in our community: people with mental health conditions; people with learning disabilities; people with autism and other communication difficulties; and people with dementia.*

The States resolved to:

*direct the Health and Social Services Department to lead the development of frameworks for people with learning difficulties, people with autism and communication difficulties and people with dementia with other relevant States Departments.*

The needs of individuals with mental health conditions would be addressed through the Mental Health and Wellbeing Strategy.

Work is still underway to define what the frameworks will include. It is expected that the development of the frameworks will incorporate the consideration and evaluation of existing care pathways against best practice. There will need to be ongoing communication between these workstreams and those in this Strategy.

As the Strategy is developed further, there may be other condition-specific need groups which will require attention – this list of the four groups (people with autism and communication difficulties, people with learning disabilities, people with dementia and people with mental health conditions) is not the complete picture. However, these particular groups of individuals are considered a priority.

This next section gives a brief overview of some of the key issues identified in relation to each group, and progress in the work already underway.

### 6.4.1 The development of condition-specific frameworks

The condition specific frameworks, which are part of the Disability and Inclusion Strategy, are for three of the four groups identified in this Strategy: people with autism and communication difficulties (though this has now been split into two frameworks, one for autism and one for communication difficulties); people with learning disabilities; and people with dementia. The fourth group, people with mental health conditions, are discussed in section 6.4.2 below.

**Recommendation 6(g):** To note that as part of the Disability and Inclusion Strategy, the Committee for Health and Social Care will be developing condition-specific frameworks for dementia, autism, and learning disabilities.

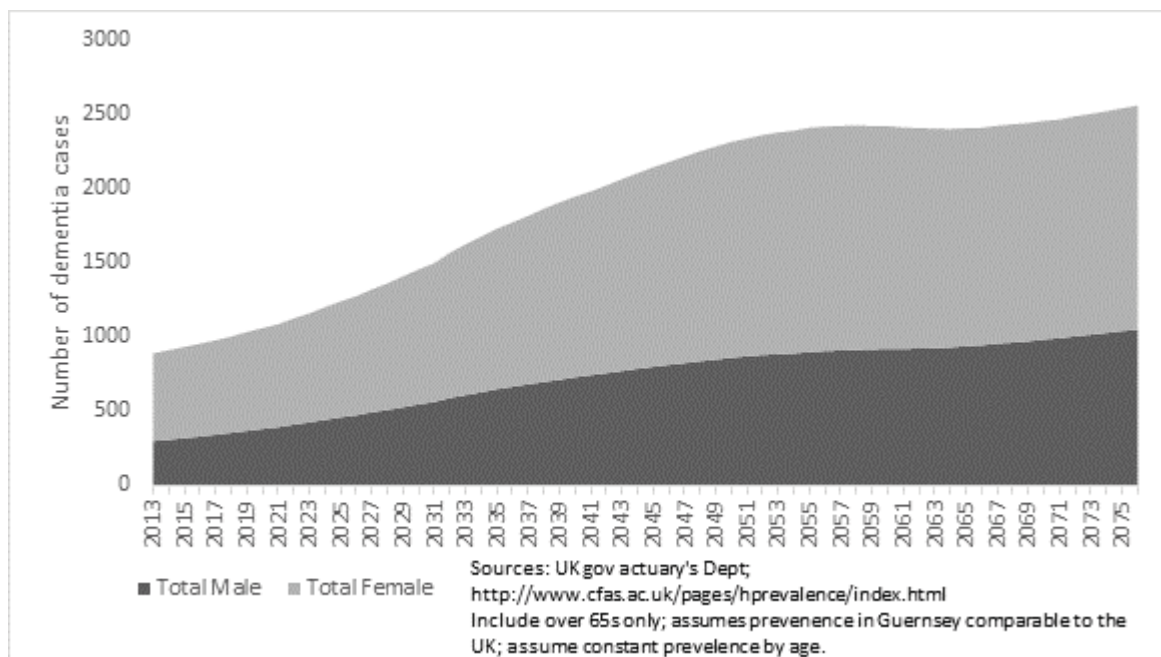
**Recommendation 6(h):** To direct the Committee for Health and Social Care that, as part of the development of these frameworks, it should seek to identify gaps in service provision and to report these to the Policy and Resources Committee with its recommendations on how these should be addressed.

### *Dementia*

The **Dementia Framework** development is being progressed. A timetable and project plan are being agreed, and a Clinical Nurse for Dementia has been appointed to lead this work within HSSD. Relevant community organisations and stakeholders will be consulted as part of this work.

Dementia is of particular concern to the Strategy. As shown in **figure 6B** below, due to the association of dementia with old age, and the increase in the population of older individuals which is anticipated, it is likely that the number of individuals with dementia will more than double in coming years. This will require not only a review of services, but also an expansion of services in order to ensure that those needs are met as effectively as possible.

**Figure 6B - Estimated total number of people with dementia in Guernsey**



Several concerns have been raised about providing for people with dementia throughout the Strategy development. These all require further investigation, whether as part of, or in addition to, the development of the Dementia Framework.

- An effective response to dementia should include a community-wide approach including pursuing **Dementia Friendly Communities** – in which bus drivers, shop assistants and members of the public have a basic awareness of the condition and are able to support people in the community when they are out and about. This is something which third sector organisations in Guernsey are already seeking to progress.
- **Awareness** and knowledge of the condition should be increased with health professionals, carers of people with dementia and the general public. This should support early identification and diagnosis.
- Improving the **quality of life** for individuals with dementia should be considered, including effective and stimulating activity programmes both in the community and in care homes. These programmes may help to slow the progression of the condition and can also support people to live well with it.
- **Specialist care** should be provided in the community and in care homes. There are limited services currently available. Thought should be given as to how to support specialist development in the private and third sector, together with the role of the States in providing high-intensity support in the most effective way possible.
- **Healthcare, re-ablement and hospital services** should all be equipped to support people with physical health problems and dementia.

As part of the SLAWS consultation respondents were asked to identify their priority areas for developments in dementia care. Although there were some technical difficulties with the responses in terms of ranking the order of importance of the following, which necessitated analysing the results by looking at weighted data sets<sup>76</sup>, the following five areas of support were noted as most important for people with dementia and their carers:

- Improved early diagnosis and intervention;
- An increase in specialist community personal care and support services for people with dementia;
- Improved professional awareness and understanding of dementia;
- Good quality information and advice for those with diagnosed dementia and their carers; and
- An increase in specialist dementia support in care homes or supported housing.

Other priorities identified by respondents included:

- Dementia specialist nurses and key workers;
- An increase in specialist care facilities for people with Dementia;
- Regular high-quality respite care including a night service;
- Needs assessments for the carers of people with Dementia;
- More stimulation for people with dementia in long-term care wards (including the Lighthouse Wards) and care homes;

<sup>76</sup> A full description of the responses to question 18 is provided in Appendix D.



- Improved public education and awareness of dementia;
- A legal requirement for all people working in care to have ongoing Dementia training;
- Introducing an EMI certificate for nursing care;
- Increased user involvement and a voice for people with dementia;
- Addressing stigma in the community;
- A GP register of patients;
- A quality outcomes framework for monitoring dementia services;
- Ongoing training and dementia champions;
- Risk assessments for carers of people with dementia;
- A social media page for carers where people can ask questions and seek support; and
- That there was a need to distinguish between dementia care and caring for individuals with challenging behaviour.

### **Autism**

At present, individuals with both autism and a learning disability can receive support through the Learning Disability Service (including residential accommodation, short-break services, community services and access to a day centre). However, if an adult has autism but does not also have a learning disability then these services are not available for them. There is, therefore, felt to be a service gap.

As reported in the Disability and Inclusion Strategy Update Report (Billet d'État XX of 2015):

*HSSD is jointly contracting with the Policy Council, Autism Guernsey and the local branch of the National Autistic Society to use the Research Director for Research Autism to help with this work. This will be funded jointly by HSSD, Autism Guernsey and the local branch of the National Autistic Society. The Guernsey Community Foundation has also agreed to fund a project post.*

*Initial meetings have taken place and work will be programmed over the next 18 months to develop the Framework for Autism.*

Although originally intended to be a framework for people with autism or communication difficulties, the decision was made to separate these frameworks and a separate framework for communication difficulties will be developed at a later date.

Autism accommodation is also under development (see 8.5 below).

### **Learning disabilities**

There is already a substantial range of services available for people with learning disabilities. These will be mapped and reviewed as part of the development of its Framework. Key concerns are related to the accommodation provision (see 8.5 below) and points of transition from family care to supported living (whether the individual moves in their late teens or early twenties or later in life).

It is intended that development of the Learning Disability Framework will sequentially follow the development of the Autism Framework.

#### 6.4.2 Support for people with enduring mental health conditions

**Recommendation 6(i): To direct the Committee for Health and Social Care that, as part of the development of the Mental Health and Wellbeing Strategy for which it is responsible, it should identify the priorities for support and service development needed by people with enduring mental health conditions and to report these to the Policy and Resources Committee.**

The Working Party has not conducted any detailed research into the needs of people with mental health conditions. However, a significant amount of research was undertaken for the Mental Health and Wellbeing Strategy in 2012<sup>77</sup>.

It is important that the needs of people with mental health conditions are taken into account. A number of concerns were raised in the consultation (see SLAWS Consultation Summary of Findings, Question 20) including that:

- There were concerns about staff turnover, retention, and on-island training opportunities.
- There were concerns about length of waiting times following referral.
- There was demand for more community services. Particularly mentioned was the importance of Support Time and Recovery (STAR) workers, the need for more preventative community based services, and the need for increased support immediately after discharge from Albecq Ward.
- There were concerns about the accommodation services (see 6.5.2 below).
- There were ongoing concerns about the level of stigma associated with mental health conditions.
- There were concerns about support for people with mental health conditions and other conditions, particularly autism.
- Provision for people with alcohol related disorders since residential facilities often did not admit people who had been drinking – that there was a need for a ‘wet house’.
- The addiction service, and whether it could include mentoring from people who had faced addiction themselves.
- An Alderney respondent felt that there was a lack of services and significant demand in Alderney.

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<sup>77</sup> HSSD (2012) *Mental Health and Wellbeing in Guernsey and Alderney: A Research Report*, available at: <http://www.gov.gg/CHttpHandler.ashx?id=80295&p=0>.

It is intended that these concerns will be largely addressed through the Mental Health and Wellbeing Strategy. Work is underway to develop an Operational Plan based upon the Strategy which will bring about changes in service provision and should be launched at the end of 2016 for service developments in 2016-2020. The two strategies will clearly need to be coordinated closely.

Work on the Mental Health and Wellbeing Strategy should identify priority actions and the changes needed to support individuals with mental health related support needs.

Consideration also needs to be given to meeting the mental health support needs of individuals who have other conditions (whether that is a learning disability, physical impairment, autism, a condition related to ageing, etc.) in a coherent and coordinated way.

Concerns about accommodation for mental health service users (6.5.2a below) and carers of people with mental health conditions (6.1 above) are explicitly addressed through SLAWS.

## 6.5 Specialised Housing and Care Home Provision

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Every person with enduring care and support needs will need to be accommodated on a long-term basis. Care and support does not have to be bed-based and is not analogous to acute hospital care provision. **A person's accommodation is their home, whether that is a room in a care home, a flat in a supported housing development, specially adapted housing, or privately owned or rented accommodation in the community.** Where an individual is accommodated is also not necessarily related to what care they can receive, since care and support can be provided in a range of housing environments.

In the past we have seen a division in care whereby it is either seen as provided 'at home' or 'in a home'. However, whether care is provided in a care home or in an individual's home it is possible for the way in which care is delivered to begin to disrupt or control a person's personal space, or overly and unnecessarily medicalise their home environment. It is important that, wherever care is delivered, it is delivered in a way that is sensitive to people's needs, dignity, privacy and sense of personal space, as well as that of other family members resident in that home.

There may be a number of reasons why some housing settings are more suited to some individuals than others. Some people may prefer the sociability of living with others in care homes or supported housing settings and make use of communal spaces and group activities. Some individuals with care or support needs have families or children with whom they wish to continue living in a family home. Housing and care decisions need to be made with sensitivity to a person's preferences, needs and personal relationships.

Housing must also be seen as an important enabler. Poor housing can disable people. If a person with a mobility problem is in a well-adapted house, which is well insulated, with a ground floor bathroom, walk-in shower, and appropriate height counters, light switches, door handles and so on, and if that property is close to local amenities, a resident may be fully capable of caring for themselves. That same person living in a multi-storey, cold, poorly designed house or flat in a more remote area may depend on people for help with food preparation, shopping, help with washing and so on, or may be more likely to move into a care home faster.

Whilst in the past we have seen a division between the idea of people being ‘at home’ versus people being ‘in care’, we need to move forward into a more nuanced understanding of people’s situations, with care and support provided in a range of housing settings. This range includes:

- **High-dependency residential care settings** such as the Lighthouse Wards or off-Island placements with on-site specialist care provision.
- **Specialised housing (sometimes referred to as housing with care)** – distinguished under the proposed land-planning use-class<sup>78</sup> as housing which provides on-site care for residents including:
  - **Care homes** where individuals are accommodated in a (usually en-suite) room with communal living spaces; care is provided on-site.
  - **Supported housing** – where individuals are accommodated in bedsits or apartments but have communal spaces (this includes extra care housing). Care is provided on-site.
- **Sheltered housing** – where individuals are accommodated in bedsits or apartments and may have a warden on-site but not regular care provision.
- **Specially adapted housing in the community** - where a house is adapted to enable a person to live independently (for example with wet-room showers or adjustable height counter tops).
- **Private or social housing** – where people remain living in standard housing in the community but where care and support is delivered to their homes.

Recent years have seen an improvement in the availability of sheltered, supported, and adapted housing with the development of extra care housing on the island, as well as the development of some supported housing (for example, Metivier House). Significant work has been undertaken by the Housing Department and Guernsey Housing Association to make this possible. However, there is demand for further development of this kind and it is likely more will need to be developed in future. There remain concerns about the limited range of options available in Alderney. There are, however, some known gaps and deficiencies in provision which are outlined below.

When asked as part of the SLAWS consultation *‘To what extent do you think that there is an appropriate quality and range of housing with care for the following groups of people?’* (Question 26), over 70% of respondents felt that there was insufficient provision of appropriate quality and range of housing with care for all groups mentioned. Appropriate identification of what types of accommodation are needed should be part of the role of the States as strategic planner (see section 3 above). Whilst some areas will require consideration as data is gathered and planning taken forward, other areas may need to be addressed more urgently, and some work is already underway to do so.

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<sup>78</sup> A new use-class proposed by the Environment Department, for debate in January 2016.

### 6.5.1 The wider housing stock and responsibility for developing specialised housing

**Recommendation 6(j): To direct that, as part of their strategic planning, the Committees for Health and Social Care, Employment and Social Security, and Environment and Infrastructure, should take account of the importance of the provision of specialist housing to meet the long-term care needs of persons with various impairments and conditions.**

#### *a) Responsibility for planning*

Having plenty of accommodation in the wider housing stock which supports people to live independently could significantly reduce the demand on care and support services. This includes ensuring that:

- new houses (in the social housing and private sectors) are built to appropriate standards of accessibility and adaptability. This should include housing appropriate for older people to downsize into. The responsibility for this will mostly fall under the Committee for Environment and Infrastructure through Building Control and the Island Development Plan.
- there is a stock of specially adapted houses to meet people's needs. Identifying the proportion of adapted houses needed and providing them should fall primarily with the Committee for Employment and Social Security with advice from the Committee for Health and Social Care.
- there are sufficient sheltered, supported, and extra care properties, where some support is available on site, to meet people's needs. Similarly, the responsibility for planning should fall primarily with the Committee for Employment and Social Security, with advice from the Committee for Health and Social Care.

#### *b) Current circumstances*

##### *(i) Wider housing stock*

Some inroads have been made into: (i) developing a range of housing options, including social housing built by the Guernsey Housing Association (GHA) to 'Lifetime Home' standards, and (ii) to promote standards that encourage developers to build new accommodation that promotes flexible living spaces.

There is a need to promote the development/redevelopment of homes that provide accessible living spaces that can be adapted to the changing needs of the individual allowing people to 'age in place'. The GHA has achieved this in its new build social housing developments and, as described in section 2, this is being promoted widely, and will become a requirement of the new Island Development Plan. The Islands are not going to be able to build sufficient new accommodation to meet needs as they arise, since the change in population and demand will be rapid over coming years. Efforts must, therefore, be taken to 'future-proof' the Islands' housing stock, by ensuring that new builds and housing undergoing renovation meet basic standards.

*(ii) Accessible and adapted housing*

The GHA has recently developed some wheelchair accessible properties. There is a need for further consideration to be given to how much demand is likely to increase with the ageing population and how many accessible properties are required.

Social Security can provide some financial support for adapting houses via Supplementary Benefit. Whilst this is means-tested, it may be available to people who could not otherwise claim Supplementary Benefit, or amounts may be available to loan where a commercial loan is not available to the person seeking to adapt their house.

*(iii) Sheltered, supported, specialised, and extra care housing*

Uptake for the new extra care housing developments has been high and there are waiting lists in operation for flats within the developments. As well as expanding the options available to older people with care and support needs, and enabling some people to regain greater independence when compared with their previous residential accommodation, the extra care housing developments have provided a kind of supported housing and independence that was not previously available on the island to working-age people with disabilities. As reported in the Update on the Disability and Inclusion Strategy:

*One of the biggest achievements over the last 2 years has been the resettlement of Learning Disabled service users from traditional long stay residential homes. In 2013 we had 61 service users living in residential care (some inappropriately placed). Today we have 26 service users in residential care and we support 47 service users in their own properties with bespoke packages of care.*

These developments are key in pursuing person-centred care, allowing individuals more independence, choice and self-determination, and providing people with equal opportunities to participate in society.

The developments have also become centres for community activities including providing venues for community events such as Brownies meetings and yoga classes.

Whether or not there needs to be further expansion of extra care housing, and if so, how this is achieved, need to be considered once there is a clearer understanding of future need and demand levels.

There is also scope for further development of other forms of sheltered or supported housing with lower levels of support delivered to them. These could be developed in partnership with, or by, private or not-for-profit providers.

Section 7.5 below outlines a proposal to expand the Long-term Care Insurance Scheme to allow funds to be used to pay for care in supported housing settings. Expanding the scheme could encourage innovation in the private and not-for-profit sectors; providing some assurance of funding for care services and therefore providing improved opportunity for developers to consider expanding the range of housing available on the Island.

### 6.5.2 Known gaps in services

#### a) *Reviewing HSSD's mental health and learning disability accommodation*

**Recommendation 6(k): To direct the Committees for Health and Social Care and Employment and Social Security to investigate the transfer of landlord responsibilities for specialist accommodation managed by the former Committee to the latter Committee, and to report to the Policy and Resources Committee no later than the end of 2017 with their findings, including the identification of any consequent redevelopment costs to provide purpose-built accommodation which will require a financial contribution from the States Corporate Housing Programme Fund.**

There are a number of properties administered by HSSD which provide accommodation for people with learning disabilities and mental health conditions. There are some general concerns with this accommodation, which can be summarised as follows:

- Most buildings utilised for this purpose are unsuitable for this use. They were not purpose-built, they have not been well-maintained, and have been developed, modified and adapted on a piecemeal basis, in response to specific challenges; and
- There has not been an over-arching strategy or plan for using this accommodation to meet identified needs. As recognised by the Strategic Asset Management Plan ('SAMP', Billet d'État XV, 2013), such accommodation has been used to meet needs as and when, rather than as part of an overall strategy or plan.

In addition to the above, there is a general lack of choice for those with more complex needs, where the options are limited to: (i) 24/7 residential care; (ii) living at home with parents/family carers; or (iii) a placement off-Island.

However, as highlighted in section 1.2 of this research report, the challenges of meeting expectations and needs are changing and there is an opportunity through this Strategy to respond positively to these challenges. Service users should have an equal opportunity to live in their own home with support.

To address specific housing issues, there is a need for the Committee for Employment and Social Security and the Committee for Health and Social Care to continue to build on the progress that has been made with the recent development of extra care housing to address specific housing needs and to look into reconfiguring services and redeveloping or replacing existing stock. In particular, there is a need to:

- Quantify the specific needs of these groups of service-users and consider how their needs can be addressed;
- Consider whether such needs can be matched appropriately to current properties available, and whether the existing property portfolio can be suitably adapted or reconfigured to meet needs;
- Understand the need for a new build programme of purpose-built accommodation for specific groups of service-users and consider the level of care and support needs of



these individuals and how they might best be addressed (i.e. through community care and support services, an on-site care and support staff or warden service, etc.);

- Investigate new or review existing strategic partnerships, for the provision of purpose-built accommodation in ways which are cost-effective for the States.
- There is a need to develop a much wider range of supported housing options, with flexible and personalised packages of care and/or support where needed.

As discussed in section 3.2.2. above, the current division of responsibilities between the Housing Department and the Health and Social Services Department have been called into question. It has been acknowledged that the Housing Department has the appropriate expertise to undertake landlord responsibilities for the properties which HSSD currently manages. Responsibility for care services would then fall under HSSD. Reflected in the restructuring of government responsibilities following the States Review Committee report, the Committee for Employment and Social Security would assume landlord responsibilities for accommodation provided by the current HSSD.

Redeveloping accommodation to provide supported living options will have a real impact on people's quality of life. Some people who were previously resident in HSSD residential homes have moved into extra care flats. This has had a significant impact on their lives, social participation, happiness and the extent to which they are able to support themselves. This is illustrated by case studies included in Appendix E where people report:

- "I am able to do so much more for myself now I have my own space!"
- "[I] have joined in many new activities offered mixing with people who may not have been friendly with me before"
- "The move to extra care housing has quite literally changed my life. I now access the community every day"

#### *b) Other known gaps in services*

Whilst the Housing Department and HSSD are already considering the redevelopment of accommodation for people with learning disabilities and people with mental health conditions, there are other groups of needs which will not be addressed as part of this work.

The needs for these developments need to be clearly articulated so that a conversation can be started with potential private and third sector partners who may be able to develop provision.

#### *(i) Physical disabilities*

The GHA has some adapted housing for people with physical impairments who are able to care for themselves or who have the support of family or friends, but otherwise services available for working-age adults with physical impairments have been very limited, with options including the Guernsey Cheshire Home, the Lighthouse Wards (for complex cases), or placement in a private sector care home.

In relation to the latter, concerns have been raised about the placement of younger people in care homes where most of the residents can be forty or fifty years older.



The opening of the new extra care housing has gone some way to provide alternative support for working-age people with disabilities. For the first time younger adults with disabilities can receive on-call support in an accessible flat in which they are supported to live as independently as possible, have their own front door, and are not dependent on family members or community services. This is a significant step forward in providing disabled adults with equal opportunities to live 'normal' lives. Further consideration needs to be given as to whether the addition of extra care housing has provided a sufficient range of options for this group, or if other developments are needed. Quantifying this need, and examining how the need should be met, should be part of the function of the States as strategic planner (see section 3 above).

*(ii) Dementia*

Many people with dementia are cared for in private and third sector care homes. There is also specialist care at the Duchess of Kent and in the Lighthouse Wards.

However, there is room for innovation in the future. People with dementia can be cared for in a range of different housing settings including supported housing settings. Other countries have successfully experimented, for example, with 'dementia villages', where people with dementia can move freely through a small community with local amenities available which are designed to promote and encourage active participation and engagement outside the individual's home under the watchful eye of carers<sup>79</sup>. There is scope for considerable innovation in how we provide accommodation and support to people with dementia.

As outlined in **figure 6B** above, there is going to be a significant increase in the number of individuals with dementia in our community. Whilst the Green Acres development will increase provision, further thought will need to be given to what types of housing provision will best meet people's needs going forward and how this expansion can be achieved.

*(iii) Autism*

There is currently no autism-specific accommodation available, though some individuals with autism are supported in off-Island placements or within the Learning Disability Accommodation Service. As reported in the Update on the Disability and Inclusion Strategy (Billet d'État XX 2015):

*Work is underway in liaison with the Guernsey Housing Association and Create design team, the National Autistic Society, and Autism Guernsey to design a purpose built autism-specific unit. The unit is due to be completed 2017/ early 2018. The design will consist of eight self-contained flats and will give us the capacity to return six service users from off-Island placements into appropriate accommodation that supports their needs.*

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<sup>79</sup> <http://hogeweyk.dementiavillage.com/en/>.

*(iv) Older people*

There are a range of options available for older people from a number of different providers, in the public, private and third sectors. These include support at home, retirement housing, supported housing, extra care housing, care homes, and specialist provision.

It is important that there is further analysis undertaken of whether the mix of different kinds of provision is appropriate at the moment. This needs to include consideration of whether there are enough supported housing developments available, and also consideration of whether there are enough specialist care homes and nursing care homes available on Island. As outlined in section 2 above, most of the care homes in the Island are currently residential care homes: it may be the case that there is greater need in future for a higher proportion of nursing care homes, or for care homes which provide care to particular groups (e.g. dementia). In some cases if specialist provision were provided by third parties - for example if there were specialist provision for people with dementia and challenging behaviour - then it may be possible to reduce the amount of specialist provision provided by the States. Consideration needs to be given to this and discussions undertaken with third and private sector partner organisations about what the barriers to expansion in more specialist kinds of provision are and whether this is an appropriate way forward.

Again, there is a need for the States to develop its strategic planning role to understand needs thoroughly to be able to provide strategic direction, and to facilitate and stimulate the private sector.

### **6.5.3 Summary**

- There is a need to actively promote the requirements of the new Island Development Plan, if accepted in its current form, to promote development/redevelopment of homes which provide accessible and adaptable living spaces to meet changing care and support needs.
- As part of developing the States' strategic planning role (see section 3 above), there is a need to:
  - (i) consider ways of working in partnership with the private and third sectors to provide supported living options for older people and younger working age adults with impairments or conditions which require an adapted environment, and/or care and support; and
  - (ii) to provide strategic direction to the private sector to develop new services and/or refocus existing provision on managing specialist areas, such as dementia care, and nursing care for those with challenging behaviours.

## 6.6 Eligibility and assessment

- **Recommendation 6(l): To direct the Committees for Health and Social Care and Employment and Social Security to review the policies and procedures by which individuals can access long-term care provided in residential and nursing homes and extra care housing , and to report to the Policy and Resources Committee with any recommendations for change by the end of 2017.**

There is a distinct division in how people are assessed for services at the moment:

- For care homes in the private or not-for-profit sector, the **Needs Assessment Panel** is used to identify and confirm someone's need level and their eligibility to access certain services.
- For those services which are provided by HSSD, a **range of different assessment methods** are used ranging from clinical assessments to confirm eligibility (e.g. for the Lighthouse Wards) to social care assessments undertaken by community staff with people in their own homes.
- There are separate prioritisation systems for individuals waiting for sheltered housing and extra care housing managed by the GHA and Housing Department.
- Similarly, Social Security undertakes its own assessment for access to **Severe Disability Benefit**.

This mix of different assessment methods and eligibility criteria can be confusing for individuals seeking to access the services. Individuals seeking to access several services (for example, sheltered housing, Severe Disability Benefit and community services) may have to undertake a number of assessments and submit the same information to different departments. Neither is it clear that the current system is effective in ensuring that individuals are placed in appropriate care settings, that they are included in decisions made about them, or that scarce care resources are put to best use.

When asked in the consultation *"to what extent do you feel eligibility criteria for services are transparent or not transparent at the moment?"*, 80% of respondents felt that eligibility criteria were "not very transparent" or "not transparent".

Two approaches to assessment and eligibility have been identified which would merit further investigation:

- **Single assessments** – in the UK a Single Assessment Process for Older People was introduced in 2001. This was intended to make the process more person-centred, coordinated and efficient: avoiding duplication. Whilst there is a single point of referral for Community Health and Wellbeing Services, thought could be given as to whether a single assessment system could be used more widely, or even cross-departmentally. Some work has been undertaken to examine whether there could be a better link between Health and Social Services and Social Security assessments.
- **Outcome based eligibility criteria** – in the UK the Care Act 2014 introduced a universal standard set of outcomes (these include for example personal care outcomes such as "being appropriately clothed" and "managing and maintaining nutrition", as well as

social inclusion outcomes such as “accessing and engaging in work, training, education or volunteering”). An individual requiring support to achieve two or more of the outcomes listed in the law is treated as eligible. This is intended to consider more holistically how a condition impacts on a person’s life in a transparent manner.

It needs to be recognised that there is a policy tension between personalisation on the one hand (i.e. allowing people greater ability to define what they need, including them in decisions, and providing them with choices) and the standardisation of eligibility criteria on the other – which could lead to a more prescriptive approach. Introducing stricter or more prescriptive eligibility criteria on who can access scarce care and support resources may, in some circumstances, be necessary in order to ensure that those most in need of services receive them, but this will come at the price of personalisation, self-direction and choice for individuals about where they wish to receive care (which may be through a more expensive form of care than can reasonably be provided). Consideration needs to be given to this balance.

It is important that any future assessment systems are:

- open, transparent, and easy to understand;
- straightforward for the service user;
- effective at preventing acute care resources from being used to meet long-term care needs; and
- effective at supporting the objectives of SLAWS for person-centred care, and including, wherever possible, people in decisions about how they receive care, whilst ensuring that their needs are met appropriately.

## 6.7 Health promotion and Public Health

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Health promotion and preventative screening programmes are key to ensuring that people do not develop preventable long-term conditions or exacerbate existing conditions, which increase their need for care and support. Whilst it is important to have effective, evidence-led health promotion programmes at the population level, it is also key to ensure that older and disabled people have access to the resources that they need in order to maintain their health – including opportunities to exercise and to eat healthy diets.

The States have agreed health improvement strategies, to reduce the harms of tobacco smoking, obesity, and drug and alcohol use. The Mental Health and Wellbeing Strategy (see section 2.1) has also been agreed, and has an important preventative element. All these factors are of major importance as causes of preventable death and premature ill health.

The States fund a range of programmes to protect the health of local residents, such as screening programmes for the prevention and/or early detection of bowel cancer, cervical cancer, breast cancer, osteoporosis, and diabetic retinopathy. The charitable Guernsey Chest and Heart provide free screenings for respiratory and circulatory diseases. There is also immunisation available against flu and shingles.

Public health interventions can not only improve health and well-being but reduce costs further down in the system<sup>80</sup>. The problem has always been to prioritise investment in prevention when there are so many immediate demands, but “a stitch in time saves nine”, so not investing is a false economy in the medium to long term. Prevention can for instance reduce the risk of expensive hospital or care admissions as well as benefitting individuals

In addition, publicly funded health services and opportunities to maintain and improve health are important for older and disabled people, and it is important that equity of access is considered.

The effectiveness of other Public Health initiatives is also key to preventing needs from escalating successfully. Low uptake of the flu vaccine, for example, could see older adults admitted to hospital this winter where this would not have been necessary had they received the vaccine. This in turn could have longer term effects on those individual’s ability to live independently. Efforts are being made to encourage people to take up the vaccine.

Effective Public Health will be key to mitigating long-term cost increases associated with an ageing population, and can help people to have a higher quality of life for longer.

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<sup>80</sup> See for example <http://www.kingsfund.org.uk/audio-video/public-health-spending-roi>.

## 6.8 Other service needs

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Three other significant areas have been raised with the Working Party during the development of the Strategy, albeit they were outside the scope of its investigations:

### ***Transition***

Young people with care and support needs are likely to undergo a transition into adult services when they are in their late teens or early twenties. Whilst this a significant time of change for anyone of that age, moving into adult services can mean uncertainty, loss of continuity, and loss of structure. People approaching transition and their carers often report that they feel they lack information about the process and feel unsupported. Services need to be aware of the need of service users for additional support at times of transition. The Children and Young People's Plan 2016-2022 has recognised that work will need to be undertaken "to ensure a smooth transition into adulthood" for those with care and support needs.

### ***Learning and employment***

The lifelong learning and employment of older people had been set aside in order to prioritise focus on care and support issues. Nonetheless, both issues were raised as part of the public consultation.

It is, therefore, important to recall that, as part of the Personal Taxation, Pensions and Benefits Review, the States agreed:

*To direct the Social Security Department, in consultation with all other relevant departments, to investigate measures aimed at supporting longer working lives and assisting older people who wish to work to remain in the workforce, and to report to the States of Deliberation with its findings no later than December 2017. (Billet d'État IV, March 2015)*

With respect to working age adults with a disability, it is recognised that education and employment are key to their social inclusion. The employment of adults with disabilities was considered as part of the Disability and Inclusion Strategy and the recent update on the Strategy explained *inter alia* that:

*...progress has been made in respect of employment matters in the form of a contract to provide supported employment services, agreed between HSSD and the Guernsey Employment Trust (GET), which includes providing assistance for disabled people to find, or to retain, employment. This will help to start changing the mind-sets of employers, whilst at the same time potentially opening up greater opportunities for disabled people. (Billet d'État XX, 2015).*

### ***Accessibility of the built environment***

Whilst there has been some discussion above around the adaptation of housing to enable people to live independently, it is also important that the wider built environment should be accessible. For example, if shopping areas and transport systems are navigable to people with

mobility or sensory impairments, then these people will find it easier to support themselves. Similarly, as discussed in section 5 above, if there are enabling attitudes towards disability within the community and there is a good public understanding of conditions such as autism or dementia, then the public environment will be likely to be more accessible for people with these conditions.

## Section 7: Developing a sustainable model for funding long-term care

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Due to the ageing population, there is already greater demand for care and support, and this will only increase, which will increase costs, with less people working to pay the taxes and Social Security contributions which fund services. Care and support costs are expected to double or triple in the next fifty years. If nothing changes Social Security's Long-term Care Insurance Fund (which covers about a third of costs, the other two-thirds being funded through General Revenue (i.e. taxation)) will run out of funds in approximately 15 years from now.

**The current funding model must be altered if the Islands are to cope with this unprecedented level of demographic change. Maintaining the status quo is not an option. To do nothing would see existing funding sources exhausted, would restrict the care options available to people and would prove to be a very expensive option for all involved.**

The funding system is not only a mechanism to support services. The way in which funding is provided affects what services providers are prepared to offer and what choices people will make about how and where to receive their care. Reviewing the funding system provides an opportunity not only to review finances to make them more sustainable, but also provides us with an opportunity to think about whether the way in which funding is arranged supports a person-centred care system, enabling people to receive the care and support that they need and want.

The complete range of information needed to resolve the funding picture fully is not currently available. The first stage in any consideration of funding should be to ensure that existing resources are deployed as efficiently as possible, but efficiencies alone are unlikely to allow us to manage the scale of change the Islands face. A three stage plan is, therefore, proposed to encourage timely changes and move towards a more sustainable system that aligns with the key principles outlined in section 1.4, particularly the need for a sustainable, yet person-centred, approach to funding:

- **Stage 1:** There is good reason to take the opportunity to act promptly to introduce at least a modest 0.5% increase in contributions to the Long-term Care Insurance Scheme. This will improve the sustainability of the scheme, whilst allowing some time for further consideration of the issues. It is possible that further increases may be needed at a later stage.
- **Stage 2:** The States should adopt a clear principle that it is responsible primarily for the 'care' element of long-term care costs, leaving individuals to pay for their own accommodation and living costs where they can afford to do so. In combination with the increase in contributions proposed in Stage 1, this would make the LTCI Scheme sustainable over the next 50 years on the assumption that the scope of the scheme were not changed (i.e. if it were to only be used for funding costs related to private and not-for-profit residential and nursing homes).



- **Stage 3:** In order to expand the options available to individuals and encourage growth in community-based provision across the private and third sector, the Long-term Care Insurance Scheme should be expanded to provide funds to allow people to arrange for care at home or care in supported housing settings to be paid for from the Scheme. This will increase the cost burden on the Scheme and requires in depth consideration of the balance of costs between General Revenue and the Long-term Care Insurance Scheme, how these will be managed, and whether further changes are required for sustainability.

This section of the report is structured as follows:

- 7.1 **Preventing cost escalation in the delivery of care** – why this is important but insufficient to control expenditure.
- 7.2 **An overview of existing funding arrangements and strategic issues**
- 7.3 **Stage 1:** Increasing the Long-term Care Insurance Fund Contributions by 0.5%
- 7.4 **Stage 2:** Care, accommodation and Living costs
- 7.5 **Stage 3:** Expanding the Long-term Care Insurance Scheme
- 7.6 **Summary**

## 7.1 Preventing cost escalation in the delivery of care

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In order to use existing resources as efficiently as possible, the cost of care delivery should be reduced where possible. This is important not only because it reduces the current expenditure but also because unnecessary cost could be multiplied as services expand to meet growing demographic demands.

The Working Party believe four core ways of preventing cost escalation should be pursued, some of which are already being pursued: controlling costs; preventing avoidable escalation of care and support needs; supporting carers; and pursuing cost-saving innovations in the way care is delivered.

The consultation asked *‘To what extent do you agree that pursuing these ways of reducing cost merits some further investigation?’*, listing:

- Innovations in ways of delivering care and support
- Support independent living
- Re-ablement
- Early intervention and prevention

90% of respondents supported the further investigation of these as cost-reducing initiatives.

### 7.1.1 Controlling costs

Costs need to be managed appropriately at two levels – firstly, by having a good understanding of the real cost of providing care in the private and third sectors and having effective Service Level Agreements to ensure value for money where public funds are provided to these sectors; and secondly, by managing costs in States-provided services.

#### *a) Understanding the value of care in the private and third sectors*

Working in partnership with significant providers of care, it is important that public sector funders gain a good understanding of what the value-for-money cost of providing care is and how grant or benefit funding relates to that cost. It is possible that some services are provided funding which is overly-generous for what they are expected to do, and others suffer from a funding shortfall.

**Many of those organisations who receive public funds at present do not have any Service Level Agreement specifying what standards are expected in exchange for those public funds. Where significant public funds are provided, Service Level Agreements should be introduced outlining the scope and quality of work to be undertaken and the responsibilities of the organisation in undertaking it.**

Understanding whether existing services are efficient in their delivery requires both the gathering of strategic information (about how much the service costs and why) and partnership working. Improving this situation should form part of the ‘building the care

community' workstream outlined above in section 3 of this report. There is a review of public-sector grant funding currently underway within Policy Council, which should feed into this work.

*b) Controlling the cost of public sector care and support services*

In 2015 Treasury and Resources commissioned BDO to benchmark HSSD services against relevant peer organisations and to use this information to set prioritised budgets based on achievable efficiencies.

BDO summarised that: "health and care services resident within both HSSD and SSD budgets are 17% more expensive than peer group,"<sup>81</sup> and summarised that, considered against benchmarked costs, they felt that there was a potential saving of £7m per annum within Adult Social Care<sup>82</sup>.

It is important to give fair consideration to why costs are lower in benchmarked jurisdictions (largely UK Local Authorities). This may be related to the division of functions between the NHS and Local Authorities, and also may be related to service quality.

Implicit in Guernsey and Alderney's situations, costs are also likely to be higher than in equivalent UK regions. The Islands may need to pay higher wages to attract similarly qualified staff. Providing the breadth of services and economies of scale that Local Authorities achieve may also not be possible when applied to our relatively small population.

Nevertheless, the benchmarking work undertaken suggests that there is likely to be significant room for savings within the system. This is something that must and will be pursued through the ongoing management of the Health and Social Care budget.

### **7.1.2 Prevention of avoidable increases in care and support needs**

Not all care and support needs are preventable or avoidable. However, in some cases there are opportunities to intervene to prevent deterioration of health and wellbeing or to help people to recover following a crisis situation and regain their independence.

As discussed in section 6 above Public Health activities, including health promotion and the development of a re-ablement service, could offer significant support to prevent individual's needs from increasing unnecessarily. Whilst these are key to the Strategy for a number of reasons, they also have the potential to prevent costs from escalating more rapidly than they otherwise would in the long-term.

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<sup>81</sup> BDO (2015) "Costing, benchmarking & prioritisation project at the Health and Social Services Department" in Billet d'État XIX 2015, p.73.

<sup>82</sup> *Ibid.*, p.74.

### **7.1.3 Supporting Carers**

Section 6 above outlined how informal carers provide a substantial amount of care and support in the community which would need to be provided by States' services if it were not provided by families and others. Whilst the decision to care should always be a personal choice, providing support to those who care informally may help them to continue in their role whilst maintaining their own wellbeing.

Whilst on the surface providing support for carers and short-break services may appear to increase costs, it is important to see the hidden costs of not supporting carers which are reflected in increased costs to public sector care and support services, effects on the availability of the workforce, an impact on tax-take, and knock-on costs related to the impact on carers' health.

### **7.1.4 Innovation**

There is the potential for both technological and social innovations in the way in which care and support are provided. Already discussed in this report are the possibility of using telehealth in Alderney (see section 4) and piloting a wider range of telecare products (see section 6).

There is potential for wider innovation in the public, private and third sectors in new and effective ways to meet people's needs efficiently. The States should encourage innovation within both its own services and the services of partner organisations.

### **7.1.5 Summary**

Whilst a significant part of the funding picture, work to reduce costs will largely be progressed as part of the development of the States strategic role in the care sector, as outlined in section 3 above, and through the ongoing budgetary management of Health and Social Services.

## 7.2 Overview of existing funding arrangements and strategic issues

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Every care and support funding system achieves a balance between the cost falling to the individual receiving the service, and the cost falling to the government (funded through taxation or social insurance). The Strategy needs to find an appropriate balance between these that is consistent across the different types of care available.

At the moment the funding balance is **not consistent, can adversely impact people's choice of care services and can be confusing**. The system is also **not sustainable**. Any decisions made to change this system need to be aware of the **strategic context**.

The total cost to the States per annum is currently around £50m. There are two main sources of public care and support funding at present:

- The **Long-term Care Insurance Scheme** – a scheme funded by Social Security contributions and administered by the Social Security Department. This is currently solely used to fund care in private and third sector care homes, and amounts to around a third of the total cost.
- **General Revenue** – this includes government income from income and other taxes and is currently used to fund all HSSD services, the domiciliary care service in extra care housing, as well as some Social Security Benefits such as Carer's Allowance and Severe Disability Benefit. This amounts to around two-thirds the total cost.

### 7.2.1 Why is the current system not consistent?

At present some services are free at point of delivery, some are entirely privately funded, and others have a mix of public and private funding as illustrated in **figure 7A** below:

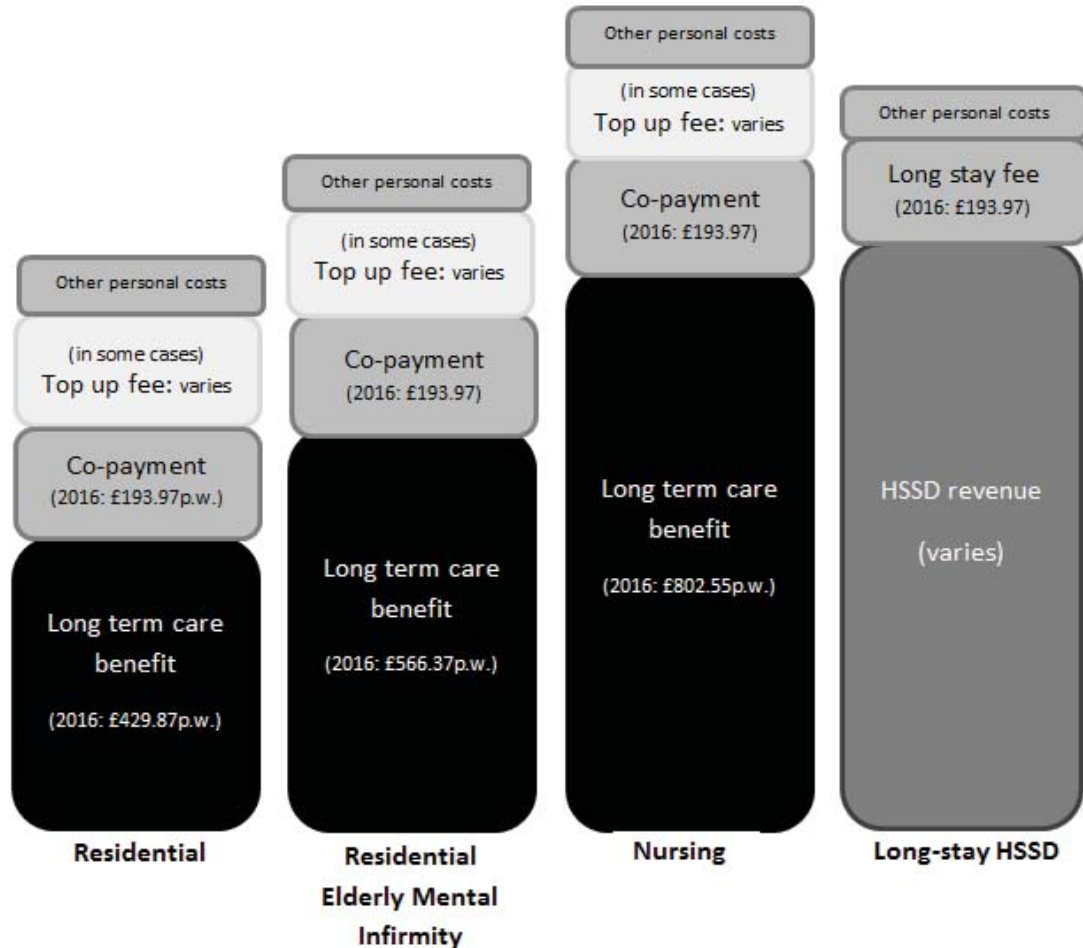
Figure 7A: How different long-term care services are currently funded in the Bailiwick

| A - General Revenue funding only  | B - General Revenue + individual contribution  | C - Long-term Care Insurance Fund + individual contribution   | D - Individual funding only  |
|---|--|---|--|
| <p>Community Services (including Senior Carers, Community Nurses, and Social Workers)</p> <p>Severe Disability Benefit</p> <p>Off-island placements</p> | <p>Continuing care hospital beds (La Corbinerie, etc.)</p> <p>Public sector residential care (Duchess of Kent)</p> <p>Public sector homes for people with a learning disability or mental health needs</p> <p>Extra care housing</p> <p>Home helps, shopping, and handyperson services</p> | <p>Private* nursing homes</p> <p>Private* specialist residential care homes</p> <p>Private* residential homes</p> <p>(*includes 'not-for-profit' provision)</p> | <p>Nursing care agencies</p> <p>Domiciliary care agencies</p> <p>Informal carers – spouses/partners and other family members <i>(may be in receipt of Carer's Allowance)</i></p> |

Taking a closer look at the Long-term Care Insurance Scheme, there are four elements to cost:

- (a) **Long-term care benefit** - this is a payment from the Social Security Department to a person or directly to a care home on the person's behalf from the Long-term Care Insurance Fund. Qualification for access to the Fund is based on residency not on the number of contributions an individual has made to the scheme. There are three different rates which reflect higher costs associated with higher need levels – nursing care, elderly mental infirm residential care (usually for someone who needs a little more attention due to dementia but does not have physical nursing needs), and residential care.
- (b) **Co-payment** – all residents will be asked to pay a co-payment to contribute towards their costs, this is a standard amount and currently less than the full old age pension (i.e. the old age pension received by someone who has made a full set of social security contributions over their working life). In 2015 the value of this co-payment was £190.75 per week (2016: £193.97 per week). The co-payment has historically been set at such a level so as to be affordable within the rate of a full old age pension, so that people in receipt of a full rate pension can afford the co-payment within their weekly income. However, some people who receive long-term care benefit are aged under 65 and others have not paid sufficient contributions to receive the full-rate. Individuals who are not able to meet this cost from their own personal resources are able to apply for Supplementary Benefit. The level of the co-payment is also linked to a long-stay fee which is charged to people who are staying in the Duchess of Kent, Lighthouse Wards and Mignot Memorial Hospital. This is charged at the same level as the co-payment.
- (c) **'Top up' fees** – Many (but not all) care homes charge more than the long term care benefit and the co-payment. The extra amount is called a 'top up' fee and is usually paid from an individual's private wealth. There is currently no limit on 'top up' fees and there is no guarantee available that individuals who cannot afford top-up fees will be able to get a bed without paying them.
- (d) **Costs not covered by the care home fee** – care home fees cover a different range of services and living costs depending on the location, but there are typically some things which are not included. This can be for things like hairdressing, chiropody, toiletries, incontinence pads etc. The individual is usually expected to meet these. A small amount (£30.37 per week in 2016) is available from Supplementary Benefit to cover these costs for individuals with no income and low savings. Individuals in receipt of a full pension and paying the co-payment would be left with only £10.48 and may be able to receive a small allowance from Supplementary Benefit to bring this amount up to £30.37 if they have no other income sources.

**Figure 7B: A summary of the costs associated with different forms of long-term care and how they are funded under the current system.**



Payment systems have arisen piecemeal over time and there is some lack of consistency in the system. Some examples of inconsistency may include:

- Individuals in some private care homes paying significant 'top up fees', whereas individuals receiving residential care in HSSD will not pay top up fees.
- Extra care housing tenants or partial owners, or residents of the mental health accommodation service pay their rent and living costs, whereas people living in residential and nursing care homes pay a set 'co-payment' which is believed to be insufficient to cover rent and living costs (see section 7.4 below).
- Most community care services are provided free of charge if provided by the public sector.
- The Long-term Care Insurance Fund can only be used for care home placements and is not available for people to engage domiciliary care privately. Some people self-fund to engage private domiciliary care and support.



- Family members who choose to care for someone at home rather than admitting them to a care home may receive Carer's Allowance and Severe Disability Benefit (which combined total around £180p.w.) whereas, if the person with care needs were admitted to a nursing care home, they would be eligible for assistance with the cost of care home fees to the order of £802.55p.w (2016 long-term care benefit nursing rate).

Consequently, there is discrepancy in:

- whether people are asked to pay, what they are asked to pay for, and how much they are asked to pay;
- where the funding is coming from (Social Security Contributions or General Revenue); and
- the extent to which the system supports personal choice (i.e. the Long-term Care Benefit supports people who privately occupy a care home but cannot support people who privately engage domiciliary care services in their own homes).

### 7.2.2 Why is the current system not sustainable?

In March 2015 the States agreed to *"acknowledge that the present model of provision of long-term residential and nursing care for older people is financially unsustainable"*<sup>83</sup> as part of the Personal Tax, Pensions and Benefits Review.

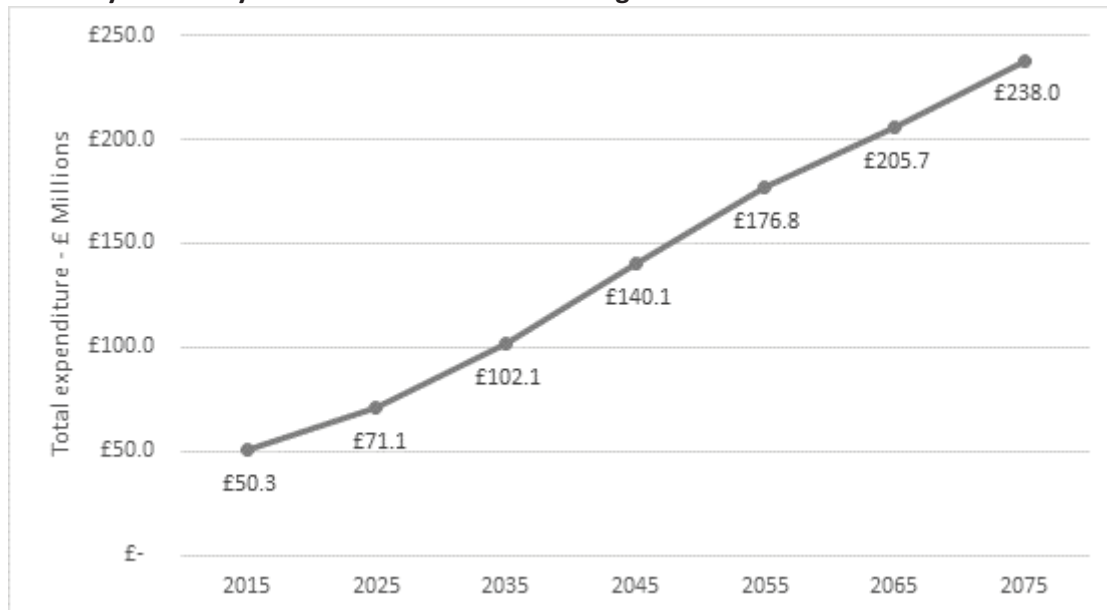
As outlined above, the two main public sources of funding are from General Revenue and the Long-term Care Insurance Fund. There is a significant difference in the funding between the two different schemes in that funds raised through General Revenue tend to be spent on services within the year they are raised. On the other hand, the Long-term Care Insurance Scheme is an investment fund which (whilst reserves are low at the moment) provides an opportunity to save for future expenditure.

Due to these differences, the two funding streams are examined separately below. However, it can be seen, based on initial projections (see Box A for details), that the Islands face a significant rise in combined expenditure, as costs will double in the next 20 years and quadruple in real terms by 2065 (see **figure 7C**).

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<sup>83</sup> Treasury and Resources Department & Social Security Department – *'Planning a Sustainable Future – The Personal Tax, Pensions and Benefits Review'* – Billet d'État IV March 2015.

**Figure 7C: Estimated combined expenditure on care and support services and benefits, as currently funded by General Revenue and the Long-term Care Insurance Fund.**



a) *General Revenue*

The majority of the cost of long-term care and support services – approximately **£32 million per annum** of the £50 million per annum total – is funded from General Revenue<sup>84</sup>. Principally, but not exclusively, this represents expenditure on services provided or funded by HSSD; the remainder of expenditure relates to the domiciliary care service provided by the Housing Department to the residents of two ‘extra-care’ housing schemes, plus the costs of two benefits – Carers’ Allowance and Severe Disability Benefit- administered by the Social Security Department.

**Figure 7D** overleaf shows the anticipated increase in expenditure for services currently funded by General Revenue.

**Central projections show that total costs are anticipated to double in real terms by 2040.**

The largest cost pressures come from those services which have both a heavy age bias and are highly labour intensive. The most significant of these fall within the Older Adult Mental Health Services (which incorporates the intensive services offered at Duchess of Kent House and the Lighthouse wards), and Community Health and Wellbeing services (which incorporate community nursing and social care services offered to people in their own homes).

<sup>84</sup> As explained in Section 4 of this research report, the money to pay for services funded by General Revenue is derived from general taxation and is funded within departmental cash limits, which are agreed annually as part of the budgeting process.

## Box A – Funding projections

Some initial funding projections have been undertaken to inform the Working Party as part of the work on the Supported Living and Ageing Well Strategy.

As with any such modelling, it is presented with the caveat that predicting the future with absolute certainty is impossible and the degree of certainty with which forecasts can be presented declines the further into the future they reach. Unforeseeable events, changes in policy, and the cumulative effect of even minor deviations from the assumed conditions will all impact the eventual outcome, making it highly unlikely that events will proceed exactly as modelled.

The projections present what is considered to be the most likely future path based on the information currently available to provide a context for long-term decision making.

The basis for the projections undertaken has been:

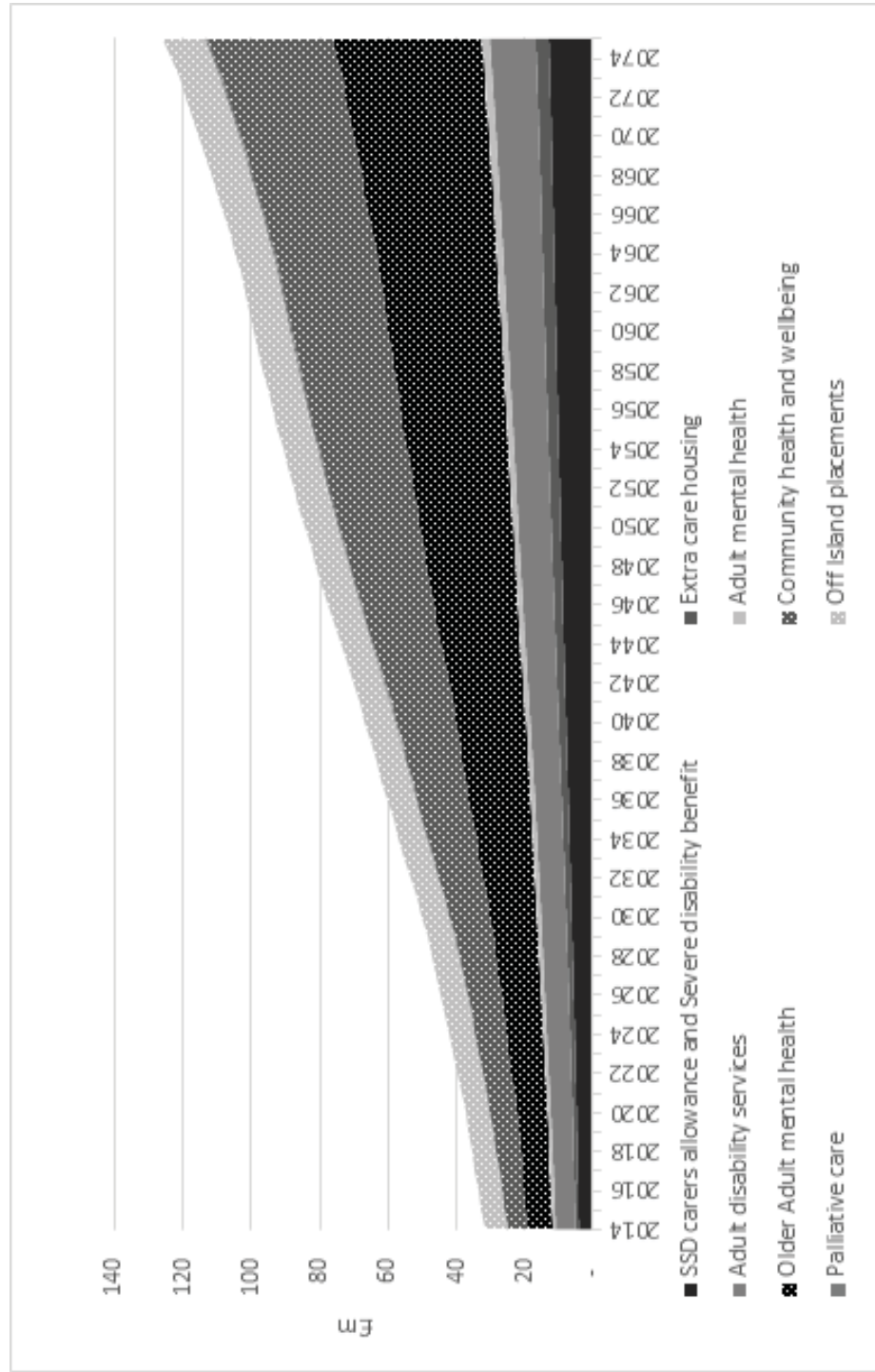
- The **unit cost** – i.e. the amount it costs to provide a bed in a care home or an appointment with community services staff (which has been informed by some of the work undertaken by BDO in HSSD). This does not include capital costs for expanding services (i.e. it includes costs related to hiring more staff but not building new facilities).
- The **current age profile of service users**.
- The **future age profile of the population based on Government Actuary's Department projections**.

The projections tell us what to expect the total cost to look like in future if the patterns of service use remain similar to what they are now but are expanded to meet rising demand.

Projections are based on the following assumptions:

- It is assumed that services continue to be provided in the same configuration and proportions that they are now.
- The projected General Revenue expenditure represents purely the operational cost of providing all these services and benefits. No provision has been made for the capital cost of any service developments that may be required to meet increased demand e.g. to build new care facilities.
- The central assumption for migration is that 200 people immigrate per year. In some cases alternative scenarios are modelled based on 0, 100 or 300 net immigration.
- All figures are presented in 2014 prices.
- Where service costs are heavily based on earnings there is an assumption that costs will increase at 1.5% per annum faster than inflation. This is based on historic trends and the need of the sectors wages to keep pace with the wages in other sectors.
- Where services have less than 75% of their costs based on wages this is reduced to 1% per annum higher than inflation, again reflecting historic trends.

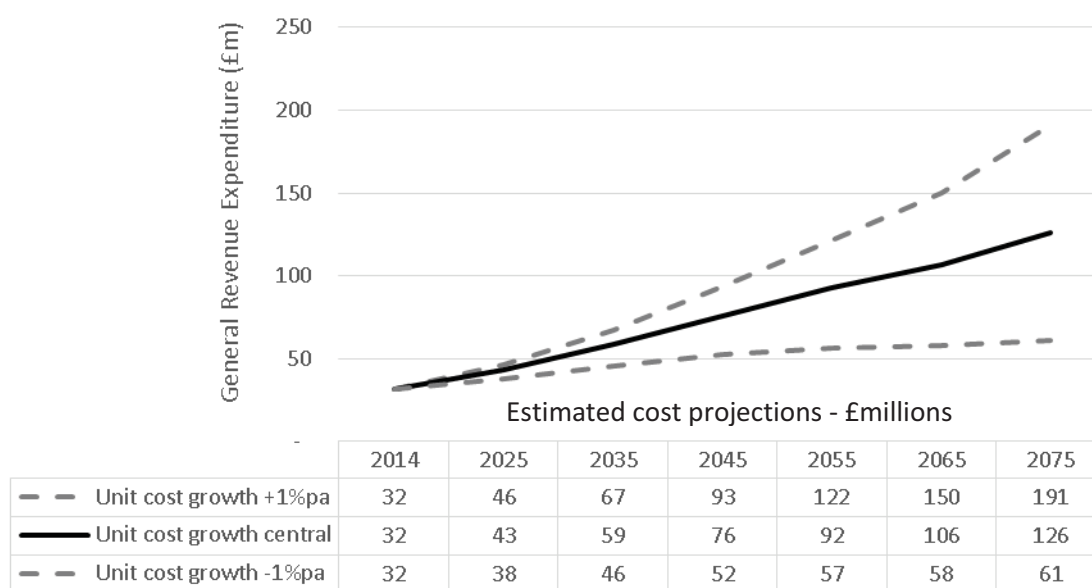
Figure 7D: Long-term expenditure of care and support services funded from General Revenue (at 2014 prices)



### Sensitivity analysis

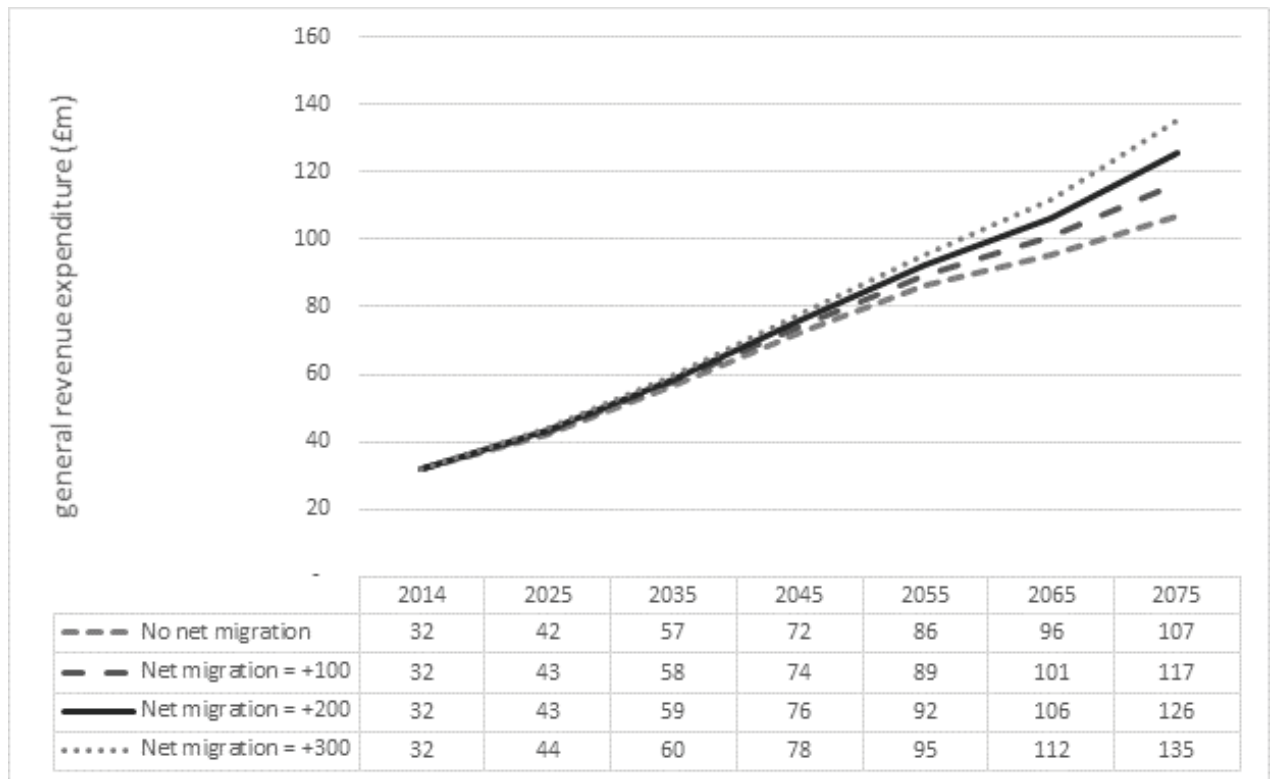
In conducting the modelling, it became clear that the key element to control General Revenue expenditure on long-term care services was the management of per unit costs, i.e. the cost per patient, per bed, or per appointment. As shown in **figure 7E** below, the modelling is very sensitive to even minor reductions or increases in the average rate of growth in the unit cost of services.

**Figure 7E: Projections of General Revenue costs - sensitivity to unit cost inflation**



If unit costs increase by just 1% per year faster than anticipated in the central projection (which could be due to wage increases to assist with recruitment, for example) the projected cost of services increases by an additional £17m by 2045 and increases the total projected cost to an estimated £191m by 2075 (compared with the central projection of £126m).

By contrast, a reduction of the assumed rate of growth in unit costs by 1 percentage point could significantly reduce the projected cost to a more sustainable level. However to achieve this, the average increase in unit cost would need to be restrained to significantly less than the assumed level of real growth in median earnings (1.5% per annum). Considering the degree to which the majority of these services are dependent on staff costs (more than 90% in most cases) controlling costs to this extent would require either a limitation on salaries (which could make recruitment and retention of qualified staff problematic), or a major structural change in the way services are delivered.

**Figure 7F: Projections of General Revenue costs - sensitivity to migration scenarios**

**Figure 7F** above shows that the modelling is less sensitive to the effects of migration levels compared with other factors. This is because long-term care services are predominantly used by older people, and immigration among older people is less common than amongst people of working age. As a result, it takes a significant length of time for an increase (or decrease) in migration to translate into an increase (or decrease) in the population of older people sufficient to make a notable impact on total costs.

#### *How much tax is needed to fund long-term care services?*

Another way to consider the costs of long-term care provision is to examine how much revenue raised through income tax is needed to finance services funded from General Revenue both today and in the future. **Figure 7G** below provides an estimation of the rate of personal income tax you would need to charge if the expenses modelled in the previous analysis were the only expense to be met from income tax payments.

This shows that to pay for these services and nothing else today, you would need a personal income tax rate of 2.8% in 2014. This means that for every pound earned (above the personal tax allowance) 2.8 pence would need to be taken in additional tax to fund care and support services and nothing else<sup>85</sup>.

<sup>85</sup> This is in addition to the 1.3 pence per pound already contributed towards the Long-term Care Insurance Fund (discussed below), meaning that at present, individuals pay 2.8 pence per pound in tax

Assuming an increase in median earnings of 1.5% a year and net immigration of 200 people per year, by 2075 the tax rate would rise to 4.3%. This means that for every pound earned (above the personal tax allowance) 4.3 pence would need to be taken in tax in order to pay for care and support services alone (not accounting for any other government services or for care home placements which are currently funded through the Long-term Care Insurance Fund, which is discussed below).

While these projections take into account the decrease in the workforce given the changing demographics, **they do not take into account increasing healthcare costs, nor do they take into account increased costs associated with the Long-term Care Insurance Scheme.** So, whilst **an increased tax rate of 1.5%**<sup>86</sup> may seem relatively affordable, it must be emphasised that this would be one of many increases needed in order to maintain services to a current standard and would only cover costs related to General Revenue, not those covered by the Long-term Care Insurance Fund (see below).

**Figure 7G** also shows the impact of varying the assumptions on migration levels and unit costs. Although the impact of the latter is comparatively greater, changes in the migration assumptions are still significant in absolute cost terms.

(N.B. At the current time there are no actuarial projections of net emigration scenarios. Given that there have been small population declines for the last two years of reported data, modelling based on such projections should be undertaken as part of the next phase of work.)

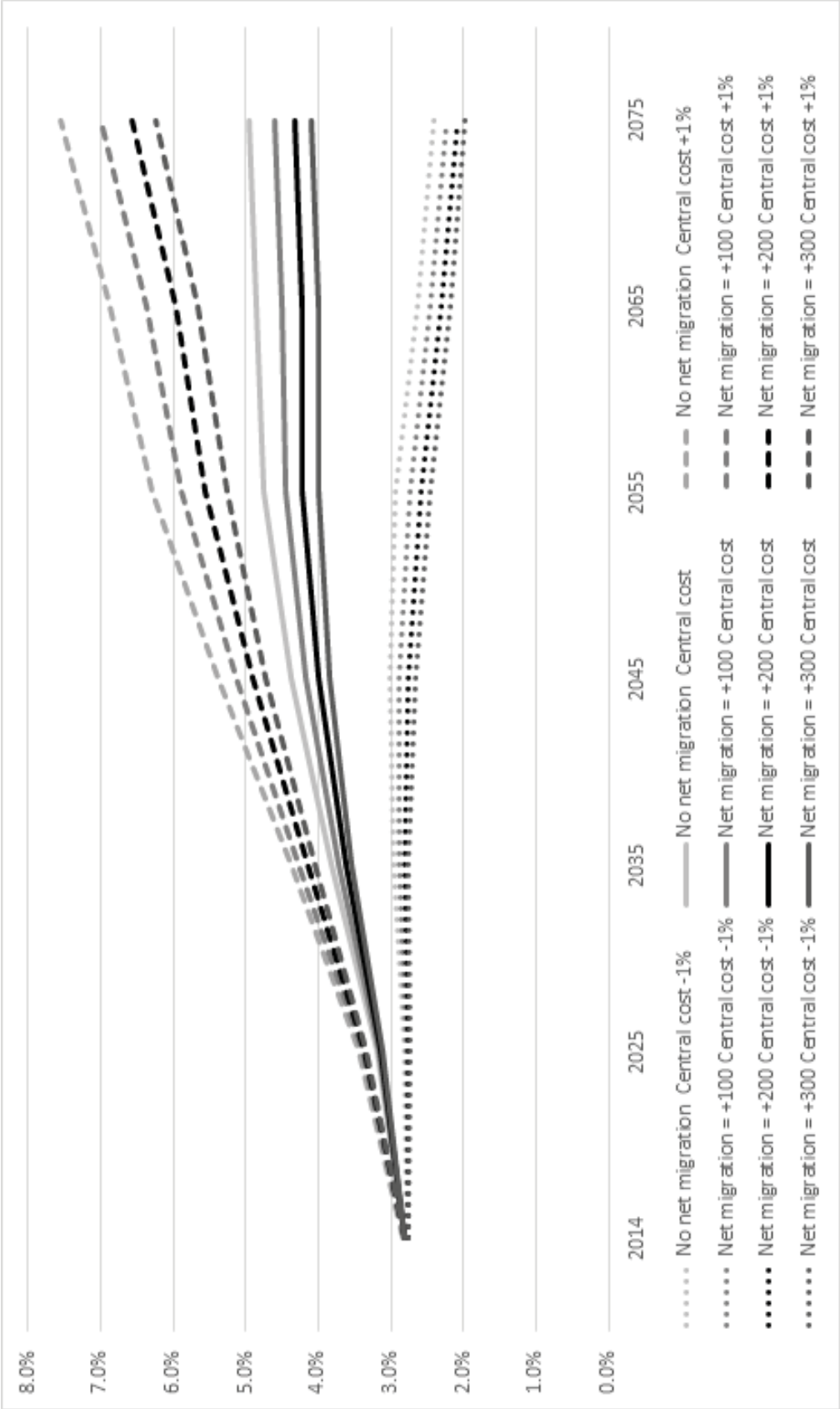
In summary General Revenue costs, especially for labour intensive, age biased services are expected to increase significantly. Funding these services would require gradual, but not insubstantial, increases in taxation unless the delivery system is changed.

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PLUS 1.3 pence per pound Social Security contributions (discussed below) bringing the total individual contribution, at present, towards care and support costs to 4.1 pence per pound of income/earnings.

<sup>86</sup> Taking the existing 2.8% tax rate for General Revenue funded care and support services and gradually introducing a 1.5% increase will increase the rate to the 4.3% tax rate which would be required by 2075.

Figure 7G: Projections of General Revenue costs showing the anticipated cost of services relative to taxation:





b) *Long-term Care Insurance Fund*

In February 2001 the States of Deliberation approved proposals from the Social Security Authority to introduce a Long-term Care Insurance Scheme<sup>87</sup> to assist individuals to meet the cost of long-term residential and nursing care delivered by private and not-for-profit care homes. The Scheme provides a weekly benefit, reviewed annually, to assist with these costs (the breakdown of which is discussed above in 7.2.1).

**In 2014, the Long-term Care Insurance Scheme provided £17.2 million of funding to an estimated number of 584 users: an average cost of £29,452 per person for the year. This covers approximately a third of total long-term care costs.**

The annual cost to the States – using the value of Long-term Care Benefit – is approximately £42,000 for a private nursing care home and approximately £22,000 for a private residential care home.

The following contribution rates apply to the Long-term Care Insurance Fund:

|                                   | Contribution rate<br>(% of income) |
|-----------------------------------|------------------------------------|
| Class 1 - Employer                | 0.0                                |
| Class 1 – Employed                | 1.3                                |
| Class 2 – Self-employed           | 1.3                                |
| Class 3 – Non-employed (under 65) | 1.4                                |
| Class 3 – Non-employed (over 65)  | 1.6                                |

These rates are paid on earnings (for employed, and self-employed) or income (for non-employed) up to the upper-earnings limit of £132,444.

Access to the Fund is based on a minimum requirement of five years' residence and is not means-tested or based on contributions paid. In fact many of the people who have benefited from the Long-term Care Insurance Scheme in recent years never contributed to the Fund, as contributions were only introduced relatively recently. The Fund is also not large enough for there to be a real sense in which the money that is put in by individual is the money which is taken out by that same individual – those paying into the Fund are funding those who have needs now. The scheme, consequently, typically redistributes resources from the younger generation to the older generation, as well as from those with low risk of developing care needs to those with care needs or a high risk of developing care needs within each generation<sup>88</sup>.

<sup>87</sup> The Long-term Care Insurance (Guernsey) Law, 2002 – available to download from [www.guernseylegalresources.gg](http://www.guernseylegalresources.gg).

<sup>88</sup> Attempting to make the LTCIS a more 'pure' social insurance scheme, by linking entitlement to contribution records, would be problematic. People who have lived in Guernsey but have a lower contribution record are probably less likely to be able to pay care costs if they need care than those with a full contribution record. Making the scheme proportionate or more strongly linked to contributions, therefore, would likely create unnecessary bureaucracy by diverting the claims of those without sufficient contributions to Supplementary Benefit. This could create a two tiered system for funding care which in many ways would be undesirable. It would also create challenges for current pensioners, who, because the scheme is relatively recent may have made only limited contribution but may, nonetheless,

As shown in **figure 7H** below, the operating surplus of the Long-term Care Insurance Fund is dwindling year-on-year and, as at 31<sup>st</sup> December 2014, was just £0.3m before investment returns, but £2.3m having taken these into account<sup>89</sup>. Current projections show a small operating surplus continuing until 2016, but it is highly likely that, without action, the Fund will fall into an operating deficit before 2020.

**Figure 7H: A summary of the financial position of the Long-term Care Insurance Fund**

|   | <b>2014</b><br><b>£ million</b> | <b>2013</b><br><b>£ million</b> | <b>2012</b><br><b>£ million</b> | <b>2011</b><br><b>£ million</b> | <b>2010</b><br><b>£ million</b> |
|---|---------------------------------|---------------------------------|---------------------------------|---------------------------------|---------------------------------|
| Income  | 18.5                            | 18.1                            | 17.6                            | 17.0                            | 16.4                            |
| Expenditure   | (18.2)                          | (17.4)                          | (16.8)                          | (16.4)                          | (15.3)                          |
| <b>Operating surplus</b>                                  | <b>0.3</b>                      | <b>0.7</b>                      | <b>0.8</b>                      | <b>0.6</b>                      | <b>1.1</b>                      |
| Investing activities                                      | 2.0                             | 4.2                             | 3.9                             | 1.3                             | 4.5                             |
| Net surplus/(deficit) in the Fund during the year         | 2.3                             | 4.9                             | 4.7                             | (0.7)                           | 5.6                             |
| Net assets of the Fund at 1 <sup>st</sup> January         | 53.3                            | 48.4                            | 43.7                            | 44.4                            | 38.8                            |
| <b>Net assets of the Fund at 31<sup>st</sup> December</b> | <b>55.6</b>                     | <b>53.3</b>                     | <b>48.4</b>                     | <b>43.7</b>                     | <b>44.4</b>                     |
| Expenditure cover in number of years                      | 3.1                             | 3.1                             | 2.9                             | 2.7                             | 2.9                             |

As at 31<sup>st</sup> December 2014, the net assets of the Long-term Care Insurance Fund stood at £55.6m, providing reserves equivalent to 3.1 years' expenditure cover.

However, as has been described earlier, without a significant change in service provision there will be increased pressure on the Long-term Care Insurance Fund to support an increased requirement for residential and nursing home care in future decades, with the result that the reserves held within the Fund – based on current contribution rates – will be insufficient to meet long-term demand. By increasing the availability of community based care services and pursuing re-ablement, the Strategy aims to reduce the rate of increase in demand for care home beds. Ideally this should help to prevent care needs from escalating unnecessarily rapidly by reducing in real terms the level of need in the community. It should also support and enable people to learn skills for self-care, reducing costs. However, if more care needs are met in other ways (i.e. through supported housing and community care) this will likely increase the need for care homes to provide specialist and high intensity care which may in turn increase the cost of the average care home placement.

*(N.B. The analysis presented below represents the outcome of internal modelling provided by Policy Council staff for the purpose of providing the Working Party with access to a flexible model with which to examine the impact of possible policy measures. While these have been aligned, as far as possible, with the modelling provided by the UK Government Actuary in 2014, there is some variation in the outcome of the two models. These variations relate primarily to*

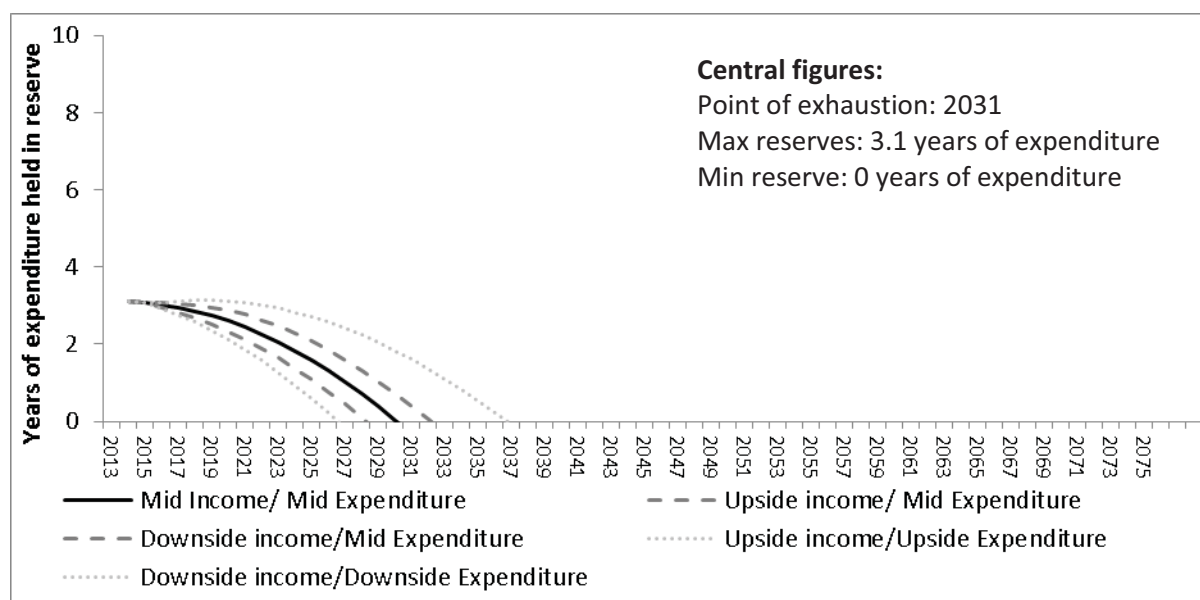
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require care and support they may not be able to fund independently. Consequently, there are reasons why maintaining a residency based eligibility criteria for the scheme seems advisable.

<sup>89</sup> Figure 10 and the financial information in this section is taken from the Social Security Department's annual report – 'Benefit and Contribution Rates for 2016' – Billet d'État XVII October 2015

the inclusion of more up to date data in the internal modelling provided by the Policy Council (i.e. that published in the 2016 Budget) and the more complex assumptions applied by the UK Government Actuary's Department in their analysis.)

**Figure 7I: Projections of reserves held within the Long-Term Care Insurance Scheme**



**The terms used in the funding diagrams can be explained as follows:**

|           |   |
|-----------|---|
| Mid:      | earnings growth averaging 1.5% p.a. with employment continuing at current rates,  |
|           | unit cost growth averaging 0.8%p.a.   |
| Downside: | income at 94% of the central projection (which has a stable employment rate and earnings growth of 1.5% p.a.) representing weak employment and earnings and/or increased rate of unit cost growth to 1.6% p.a.        |
| Upside:   | income at 106% of the central projection (which has a stable employment rate and earnings growth of 1.5% p.a.) representing buoyant employment and earnings growth and/or reduced rate of unit cost growth to 0% p.a. |

Using central projections, **Figure 7I** shows that reserves in the Long-term Care Insurance Fund are expected to run out in approximately 2031; well before the Island's burgeoning older age population has reached its peak.

In its most recent uprating report, the Social Security Department stated the following in relation to the sustainability of the Long-term Care Insurance Scheme (Billet d'État XVII 2015) (paragraphs 168 and 169):

*"The actuarial review of the Long-term Care Insurance Fund for the years 2006 to*

2009, inclusive<sup>90</sup>, and projections to 2070, appeared in the appendix to the Billet d'État XV of 2011. The review showed that the current rate of contribution for the Long-term Care Insurance Fund, which is 1.3% of earnings for an employed person, is unsustainable. Based on the assumptions used in the review, if the rate remained unchanged, the reserves of the fund would be exhausted by around 2027.

*Based on an interim review of the Long-term Care Insurance Fund, which was fully reported in paragraphs 130 to 134 of the Department's Report regarding Benefit and Contribution Rates for 2015 (Billet d'État XXI of 2014), an increase in the rate of social security contributions of anywhere between 0.6% and 1.9% may be required to make the Fund sustainable in the long-term, depending on the particular assumptions applied concerning contribution income, permanent nursing care benefit expenditure, and benefit uprating policy. At the level of contributions and grant received today this is equivalent to approximately £7m to £22m of additional funding per year."*

**The Working Party considers this a wholly unsustainable position. Unless other means are introduced to fund long-term care services or to bring additional revenue into the Fund, there will be a significant shortfall to meet demand in future decades.**

**It must also be noted that any required increase of 0.6% to 1.9% in Social Security contributions would be in addition to the increase of approximately 1.5% in tax outlined above, if the system was not changed. This could lead to an increase of between 2.1% and 3.4% in tax and contributions combined – i.e. an additional 3.4 pence per pound in earned income paid towards publicly-funded care and support, a rise from the current level of 4.1 pence in the pound to 7.5 pence in the pound by 2075.**

There is also some urgency in addressing this issue. Whereas in relation to other Social Security benefits increasing the immigration of working age adults may ameliorate these concerns, the short lifespan before the Fund is expected to be exhausted means that effects of positive immigration on the Fund has very limited impact.

It should also be noted that the Long-term Care Insurance Fund offers the unique opportunity to save for the future. This means that a relatively small increase introduced sooner, with funds saved and invested, could generate income and thus cushion future demand. To introduce the same change at a later date would not only lose the years of income which could have been saved, but also the investment returns. Therefore, if contribution increase is required, to act sooner is preferable to waiting.

*c) Individual contributions and self-funding*

Whilst the focus has been on public funding, as outlined in 7.2.1 there are areas where individuals are already paying significant contributions. These include:

- Co-payment and long-stay fees for private and not-for-profit care homes, the Duchess of Kent, the Mignot Hospital Continuing Care Ward and the Lighthouse Wards.

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<sup>90</sup> The next full actuarial review of the Fund, covering the period 1st January 2010 to 31st December 2014, is underway and due for completion in early 2016.

- Rental and living cost charges to individuals living in HSSD accommodation for people with Learning Disabilities and people with Mental Health conditions.
- Top-up fees – (see 7.2.1 above) to private and not-for-profit care homes.
- Rent and service charges in extra care housing.
- Charges for Home Helps, the Shopping Service, and Handyperson Service.
- Privately engaged domiciliary care.
- Purchase of equipment.
- Costs incurred by individuals in order to act as an informal carer (perhaps lost earnings, for example).

There is not currently a full picture of how much individuals are spending on care and support. Where an individual is expected to contribute to one of the above but is unable to, most of the costs are covered by Supplementary Benefit.

*(i) Supplementary Benefit*

£700,000 to £800,000 of annual Supplementary Benefit expenditure relates to helping those who cannot meet the cost of the Long-term Care co-payment for care home fees, in full or in part. Access to support is means tested. However, the primary property asset ('family home') is not taken into account in the means-test of assistance for support with costs associated with a care home placement.

An estimate of the percentage of residents in care homes requiring Supplementary Benefit assistance to meet the co-payment is as follows:

|                                  |            |
|----------------------------------|------------|
| <b>Residential care</b>          | <b>22%</b> |
| <b>Residential with EMI care</b> | <b>18%</b> |
| <b>Nursing care</b>              | <b>34%</b> |

In addition, care home fees cover a different range of services and living costs depending on the location, but there are typically some things which are not included. This can be for things like hairdressing, chiropody, toiletries, incontinence pads etc. The individual is usually expected to meet these additional costs from their own resources, although a small amount (about £30 a week) in the form of a 'personal allowance' is available from Supplementary Benefit to cover these costs for individuals with no income and low savings.

Additional payments are made from Supplementary Benefit to support people with costs in other care settings including, for example, extra care housing and the mental health accommodation service.

*(ii) 'Top up' fees*

Many (but not all) care homes charge more than the combined cost of Long-term Care Benefit and the co-payment. The extra amount is called a 'top up' fee and is usually paid from an individual's private wealth. There is currently no limit on 'top up' fees and there is no mechanism for guaranteeing that beds will be available to someone who cannot afford to pay a 'top up' fee.

There is little data available about the value of 'top up' fees charged by private sector residential and nursing care homes. However, it is believed that 'top up' fees vary from tens of pounds to hundreds of pounds each week. It has also not been possible to ascertain how people pay these fees, whether they are paid for by the individual or their families.

However based on 2013 information, it is understood that of the 21 private and third sector care homes in operation at that time:

- 4 homes charged all of their beds at 'States' rates' (i.e. the value of the benefit available from the Long-term Care Insurance Scheme, plus the co-payment);
- 13 homes charged 'top up' fees for some beds; and
- 4 charged 'top up' fees for all beds.

Whilst some care homes may claim to have better facilities or services for charging higher fees, individuals attempting to assess their options for care homes do not necessarily have any clear way to compare the facilities and services available in each home without visiting and gathering their own information. It is also considered that care homes will add or increase such fees at times of high demand. When demand is lower, more beds become available at 'States rates'.

Furthermore, there is no control on the allocation of beds at the lower rate. The cheaper beds are currently taken on a first come first served basis and are not reserved for those who are less able to pay. However, the Working Party has no evidence to suggest that a significant number of people are unable to access a place in a home because they cannot afford 'top up' fees. (The questions of access, eligibility and affordability of care home placements are discussed further in Section 6).

Generally speaking, financial assistance is not available from Supplementary Benefit to assist with the cost of 'top up' fees charged by some private sector residential and nursing care homes.

In summary, individuals are already bearing some of the cost of care and support. The full amount has not been quantified to date. For some aspects of cost, where an individual is asked to pay but unable to, Supplementary Benefit can provide means-tested assistance (which, for care homes, does not take into account the value of the primary property). For other aspects, such as top-up fees, public assistance with costs is not available.

### 7.2.3 What are the strategic constraints?

There are some strategic constraints on the decisions which can be made to address the funding situation. Primarily, consideration needs to be given to the Fiscal Framework and to the founding principle of the Long-term Care Insurance Scheme.

#### a) *The Fiscal Framework*

The Fiscal Framework is intended to set clear parameters in regard to the fiscal conduct of the States (i.e. how much tax, borrowing etc. is permissible for the government), committing the States to long-term financial balance and limiting the size of the public sector.

The States resolved in the Personal Taxation, Pensions and Benefits Review:

*“To direct the Policy Council to ensure that the outputs of the Supported Living and Ageing Well Strategy can be achieved within the financial limitation set out by the Fiscal Framework [that placed an upper limit on aggregate government income, incorporating General Revenue, Social Security contributions and fees and charges, such that total government income should not exceed 28% of Gross Domestic Product].”<sup>91</sup>*

This means that the Strategy cannot raise tax or contribution rates indefinitely to meet rising demand and costs, but only in moderation and within the financial limitations of the Fiscal Framework.

#### b) *The Long-term Care Insurance Scheme*

The principles on which the Long-term Care Insurance Scheme were based when the scheme was agreed by the States in 2001 can be altered. However, changes to the scheme should be cognisant of some of the key principles:

- The scheme was limited in coverage to private sector residential and nursing care homes;
- Care funding should be based on residency rather than a means-test;
- There was an “implicit commitment” with the introduction of the insurance scheme that people should not be forced to sell the family home to pay for long-term residential or nursing care. As such, eligibility for the scheme would not take property ownership or capital resources into consideration;

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<sup>91</sup> Treasury and Resources Department & Social Security Department – ‘*Planning a Sustainable Future – The Personal Tax, Pensions and Benefits Review*’ – Billet d’État IV March 2015.

- The insurance scheme should not distort the way people receive care in Guernsey and Alderney, i.e. it was not the intention for funding to result in a less developed community care provision;
- Long-term care should where possible be provided in an appropriate setting according to an individual's need and preferences. This could be in people's own homes in the community. The aim should be for people to stay in their own homes as long as possible;
- Though the principle of sheltered or extra-care housing was supported, there was a decision that funding from the LTCIS would not be extended to cover these forms of provision at that time. However, there was recognition that if sheltered housing costs were broken down into accommodation, services and care, it could be argued that the latter should be covered by the scheme;
- There would be no further cash benefits provided to carers;
- A multi-disciplinary Needs Assessment Panel<sup>92</sup> would be established to assess the level of need of people to be admitted to care;
- States-provided residential homes and long-term hospital care were excluded for reasons relating to policy and administrative ease, and it was agreed that these would not be funded from the scheme;
- It was agreed that respite care should be funded by the insurance scheme; and
- The report expressed support for the Board of Health's intended changes in the standards for, and inspection of, residential and nursing homes.

#### 7.2.4 Summary

The current funding system is not sustainable, contains some significant inconsistencies, and must be changed to make it fit for the future. If nothing is changed but income levels then (between Social Security contributions and tax) Islanders would need to pay something in the order of an extra two to four pence per pound in order to maintain the current level of services in future. However, increasing tax or contributions indefinitely is not an option. Other costs, including health care costs, will be rising at the same time and may also require tax increases if current service levels are to be maintained. The opportunity must also be taken to restructure the health and social care system to make it more sustainable.

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<sup>92</sup> The Needs Assessment Panel is a multi-disciplinary team of health and social care professionals who determine individual care needs for the purpose of the Long-Term Care Insurance Scheme. They may determine an individual's needs to be met appropriately through community care, sheltered housing, extra care housing, residential or nursing care.



### 7.3 Stage 1: The case for immediate increase of contributions to the Long-term Care Insurance Fund

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**Recommendation 7(a): To direct the Committee for Employment and Social Security, as part of its 2016 uprating report, to bring forward proposals to increase contribution rates to the Long-term Care Insurance Fund for employed, self-employed and non-employed persons by no less than 0.5% from 1<sup>st</sup> January 2017.**

As explained in 7.2.2b) above, the Long-term Care Insurance Scheme is soon expected to be running an operating deficit due to increasing demand and the Fund is expected to be exhausted in around fifteen years from now.

Even if services are run more efficiently; prevention of needs arising and increasing is pursued; services are restricted; funding systems are restructured; and individuals contribute more towards their costs, there is likely to be a need for some more public funding to be raised to support those unable to otherwise pay for their care and support costs.

There are advantages to acting sooner rather than later. Today's surpluses will bolster tomorrow's investment income which will, in turn, extend the life of the Fund in a way which will otherwise, in the long-run, cost the tax payer more.

It is also clear that at present there is substantial work still to be undertaken to gain a clear picture of how to create a balanced and sustainable funding system going forwards. Other changes to improve the sustainability of care and support funding may take longer to implement. Time is passing and the point of predicted exhaustion of the Fund draws closer.

As a method of funding long-term care in the future, there is substantial public support for increasing contributions in preference to other funding scenarios. The public consultation asked how funds should be raised if further public funds were needed. 65% of respondents thought that Social Security contributions should be raised (some of these supporting an increase in combination with a tax increase). Only 11% thought that under no circumstances should tax or contributions be increased.

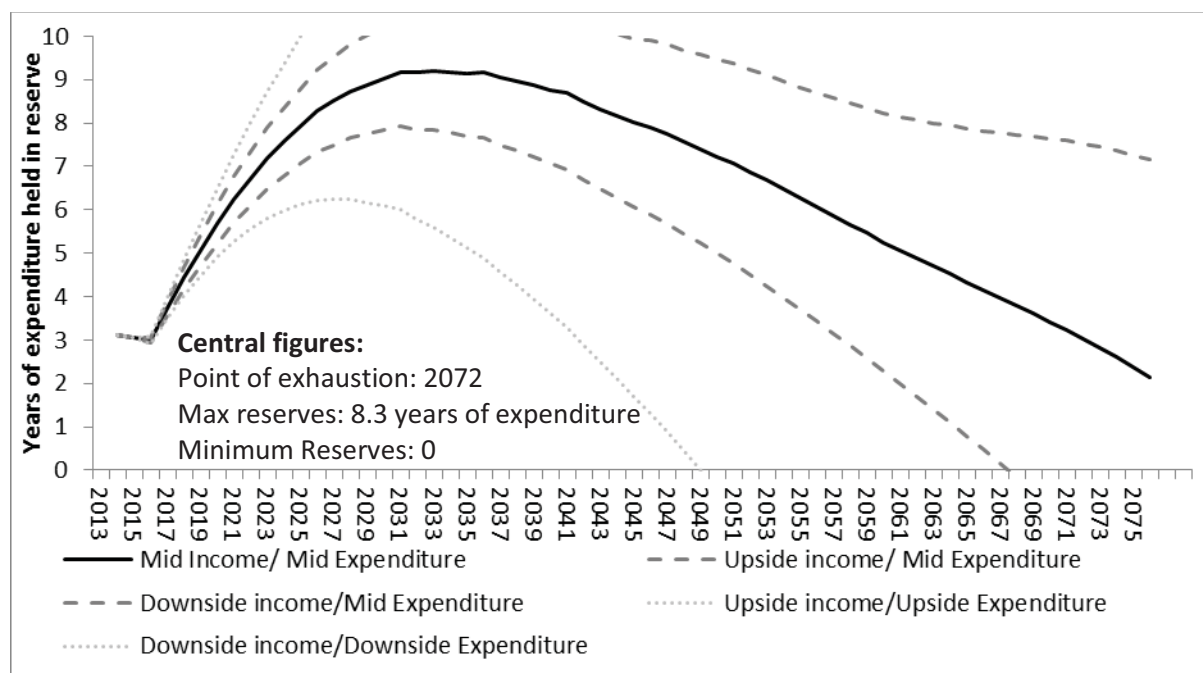
The key question, therefore, becomes: **if an increase in Social Security Contributions is inevitable, and acting sooner has significant pay-back, how much is it appropriate to raise Contributions at this stage?**

a) *How much would be needed to make the fund sustainable?*

One way to answer this question would be to ask how much would be needed to make the fund sustainable in its current form and to increase contributions by that amount.

Modelling suggests that increasing contribution rates by 1.1% (i.e. individuals paying an extra 1.1 pence per pound into the Fund in addition to the Social Security contributions they already make) would make the Fund sustainable for the next 50 years, as shown in **figure 7J** below:

**Figure 7J: The effect on the Long-Term Care Insurance Fund of increasing contribution rates by 1.1% (without changing the scope of services receiving funding)**



Overall a 1.1% increase in contributions would raise an additional sum of approximately **£16 million** in 2017, equivalent to approximately 0.7% of Gross Domestic Product (GDP).

In terms of operating within the States-agreed Fiscal Framework, applying a 1.1% increase to the contribution rate would bring estimated aggregated income in 2017 to approximately 25.5% of GDP, again well within with the 28% limit agreed by the States as part of the Personal Tax, Pensions and Benefits Review<sup>93</sup>. However, as outlined above we know that there would also need to be an increase of around 1.5% in general taxation to cover increasing demand on General Revenue funded services. (This would mean a total increase of 2.6%, i.e. an additional 2.6 pence per pound, within the range of the 2.1%-3.4% total increase outlined above).

For individuals and different cohort groups, a 1.1% increase in contributions would result in an additional (approximate) weekly contribution to the Long-term Care Insurance Fund, as shown in the **table 7A** below:

<sup>93</sup> As GDP growth has outstripped revenue growth in the last five years, the size of income relative to GDP has decreased.

**Table 7A: The cost of a 1.1% increase in Social Security contributions for different cohort groups**

|                       |                | Gross income (not equivalised <sup>94</sup> ) | Estimated additional payments per annum for a contributions increase of 1.1% |
|-----------------------|----------------|---|--|
| Single adult          | Lower quartile | £11,985                                       | £132   |
|                       | Median         | £25,033                                       | £275   |
|                       | Upper quartile | £40,138                                       | £442   |
| Couples with children | Lower quartile | £54,325                                       | £598   |
|                       | Median         | £79,260                                       | £872   |
|                       | Upper quartile | £112,437                                      | £1,237   |
| Single pensioner      | Lower quartile | £12,125                                       | £-   |
|                       | Median         | £17,540                                       | £115   |
|                       | Upper quartile | £29,270                                       | £244   |
| Pensioner couple      | Lower quartile | £26,067                                       | £-   |
|                       | Median         | £38,079                                       | £53  |
|                       | Upper quartile | £61,976                                       | £316   |

The Working Party has, therefore, examined the effect on the Long-term Care Insurance Fund of increasing contribution rates paid by individuals by between 0.5% and 1.1% from 1 January 2017.

However, it is not clear that this is the right approach to take at this stage:

- It is important that service structure, funding structures and the balance between individual contributions and States' funding are considered. A significant increase could cause complacency in resolving these issues or in reviewing the situation 'in the round'.
- It is also important to consider that even a 1.1% increase would not 'fix' the problem – since the Long-term Care Insurance Fund covers only a third of the total care and support costs.

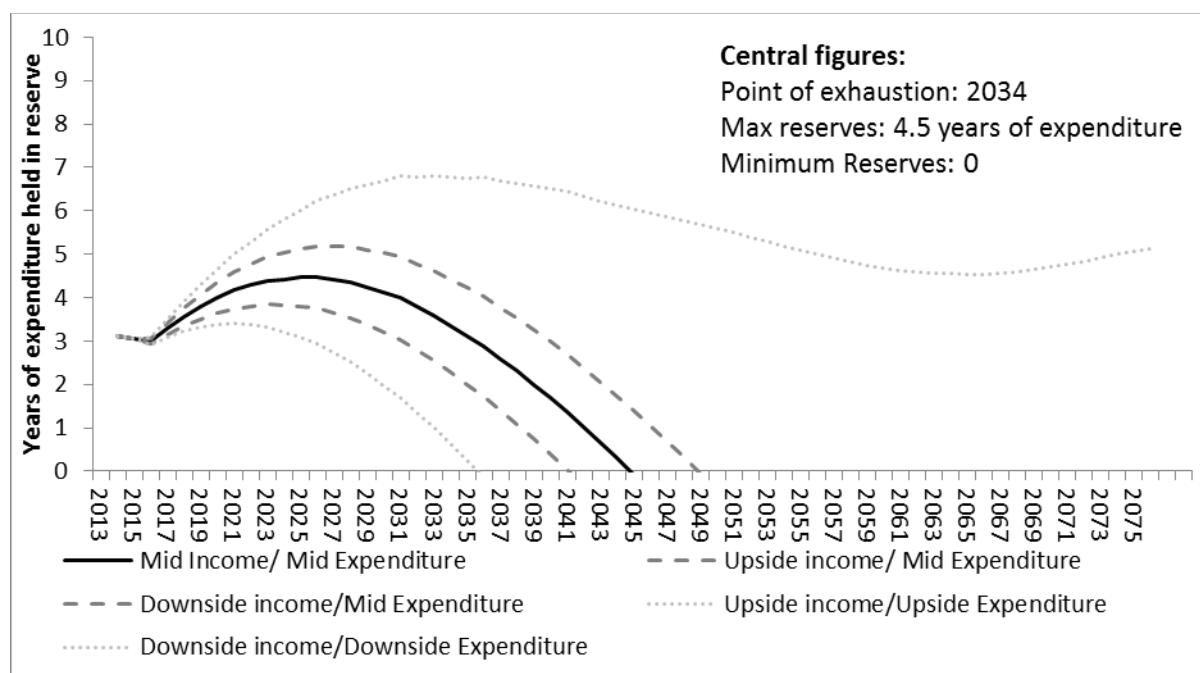
Nevertheless, on balance, the Working Party considers that the opportunity to increase funds should not be missed for the reasons set out below.

*b) Increasing the Long-term Care Insurance Fund contribution rates by 0.5%*

**Figure 7K** below shows that even a relatively modest increase to contribution rates of 0.5% has the potential to prolong the longevity of reserves within the Long-term Care Insurance Fund.

<sup>94</sup> Based on internal tax data.

**Figure 7K: The effect on the Long-Term Care Insurance Fund of increasing contribution rates by 0.5% (without changing the scope of services receiving funding)**



Whereas **figure 7I** showed that, without any increases to the rate of Social Security contributions or changes in the services funded from the Long-term Care Insurance Scheme, the Fund would be exhausted in the year 2031, **figure 7K** shows that a 0.5% increase to the contribution rates should be sufficient (based on current population forecasts) to maintain the Fund until 2045.

**A 0.5% increase in the contribution rate therefore increases the longevity of the reserves in the Fund by a period of 14 years.**

Applying a 0.5% increase in contributions to employed, self-employed and non-employed persons would raise approximately an additional **£7 million** in 2017. This would be equivalent to approximately 0.3% of Gross Domestic Product (GDP) and bring estimated States' aggregated income in 2017 to approximately 25.1%, well within the maximum of 28% of GDP agreed in 2015<sup>95</sup>.

For individuals and different cohort groups, a 0.5% increase in contributions would result in an additional (approximate) weekly contribution to the Long-term Care Insurance Fund, as shown in **table 7B** below:

<sup>95</sup> As GDP growth has outstripped revenue growth in the last five years, the size of income relative to GDP has decreased.

**Table 7B: The costs of a 0.5% increase in Social Security contributions for different cohort groups**

|                       |                | Gross income (not equivalised <sup>96</sup> ) | Estimated additional payments per annum for a contributions increase of 0.5% |
|-----------------------|----------------|---|--|
| Single adult          | Lower quartile | £11,985                                       | £60  |
|                       | Median         | £25,033                                       | £125   |
|                       | Upper quartile | £40,138                                       | £201   |
| Couples with children | Lower quartile | £54,325                                       | £272   |
|                       | Median         | £79,260                                       | £396   |
|                       | Upper quartile | £112,437                                      | £562   |
| Single pensioner      | Lower quartile | £12,125                                       | £-   |
|                       | Median         | £17,540                                       | £52  |
|                       | Upper quartile | £29,270                                       | £111   |
| Pensioner couple      | Lower quartile | £26,067                                       | £-   |
|                       | Median         | £38,079                                       | £24  |
|                       | Upper quartile | £61,976                                       | £143   |

*c) Conclusion*

Whilst the Working Party acknowledges that a 1.1% increase in contribution rates could sustain the Fund in the long-term, it is not recommending an increase of this amount at this time, as it considers that other measures, such as individuals being asked to contribute more towards their own long-term care and support (see 7.4.2. below), should be further investigated. However, the Working Party does not believe that the Fund can be made sustainable without some short-term increase in income in particular, because the sooner action is taken, the sooner the benefits of the investment of reserves can be felt to reduce further contribution increases in the future.

The Working Party, therefore, recommends that as a first phase, and in the context of a package of recommendations on funding issues, the States be asked to direct the Committee for Employment and Social Security, as part of its 2016 uprating report, to bring forward proposals to increase contribution rates to the Long-term Care Insurance Fund for employed, self-employed and non-employed persons by no less than 0.5% from 1<sup>st</sup> January 2017, to improve the sustainability of the Long-term Care Insurance Fund. However, this measure must not be adopted in isolation but alongside other recommendations in the strategy, as it is not sufficient in and of itself to 'solve' the funding issues the Islands face. In particular, it does nothing to address cost pressures on General Revenue funded services. Neither does it address the fact that the Fund is only available for a very specific type of care provision (that provided in care homes), and is not accessible to others to access private or third sector care and support in their own homes – this is addressed in Stage 3 below.

<sup>96</sup> Based on internal tax data.

## 7.4 - Stage 2: Care, accommodation and living costs

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**Recommendation 7(b):** To agree, in principle, that wherever care and support is received, for accounting and charging purposes, the costs associated with the provision of long-term care services should be separated into three distinct areas: accommodation; day- to-day living expenses; and care and support.

**Recommendation 7(c):** To agree, in principle, that the Long-term Care Insurance Scheme should be used to meet the costs of care and support only, with payments for accommodation costs and living expenses being the responsibility of the individual receiving care and support.

**Recommendation 7(d):** To agree, in principle, that where an individual receiving long-term care was unable to meet their accommodation and living costs in full, they would be eligible for means-tested assistance via Supplementary Benefit.

**Recommendation 7(e):** To direct the Committee for Employment and Social Security Committee, in conjunction with the Policy and Resources Committee, to investigate in detail the implications for contributors, individuals, and the States of the implications of the principle that the Long-term Care Insurance Fund should cover care and support costs only, and to report to the States with its findings and recommendations no later than October 2017.

**Recommendation 7(f):** To agree that the investigation of this principle shall be limited, at this stage, to the implications related to care and support provided to individuals in public and private sector residential and nursing homes.

**Recommendation 7(g):** To note that any costs associated with the investigation of this principle will be met from the Long-term Care Insurance Fund.

### 7.4.1 The principle: accommodation, living and care costs (Recommendations 9b, c, d)

As discussed in 7.2 and 7.3, whilst it would be possible to increase tax or Social Security contributions to cover rising costs, there is a limit to the extent that this is desirable, particularly in the knowledge that the ageing population will create cost pressures in other areas of government (e.g. healthcare and pensions) as well as for care costs, and there is a desire to keep the size and cost of the public sector within 28% of GDP.

Consequently, the balance between the amount that the States pays and the amount that the individual pays needs to be considered. A decision needs to be made about what, in principle, the States should be responsible for funding.

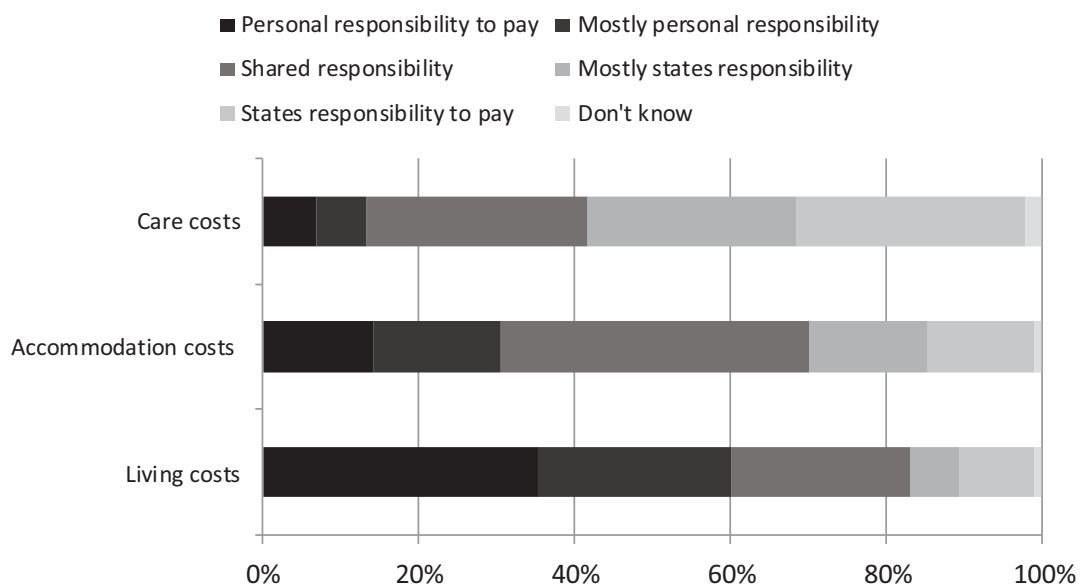
To investigate the development of such a principle, the Working Party revisited some earlier work carried out in 2011/2012 by **'The Funding of Long-term Care Working Party'**<sup>97</sup>. Whilst Islanders are generally accustomed in Guernsey and Alderney to all inclusive charges being levied for residential and nursing home care, the Working Party acknowledges that these costs could be broken down into three separate components, namely:

- **day-to-day living expenses** (e.g. food, clothes)
- **accommodation costs** (e.g. rent, service charge)
- **care and support costs** (e.g. the wages of a professional carer)

The public consultation asked *"Where people can afford to pay, should the States or the individual bear more of the responsibility?"*

Whilst the majority of respondents (60%) supported the individual being all or largely responsible for funding their living costs, there was a majority (56%) expectation that the States should cover all or most care costs; opinion was divided on accommodation costs. This is shown in **figure 7L** below:

**Figure 7L: Responses to q.35 of the SLAWS consultation: 'Where people can afford to pay, should the States or the individual bear more of the responsibility?'**



Living and accommodation costs are common to everyone in the Islands, so it is arguably inequitable that those people who receive care and support in residential or nursing homes have some of those costs met by the States via tax funding, when tax payers more generally may be struggling with these costs and many of those receiving care are in a position to cover

<sup>97</sup> The **'Funding of Long-Term Care Working Party'** was formed in mid-2011 to examine the wide ranging and complex issues surrounding the funding of long-term care. It was formed in response to the political concerns about the sustainability of the revenue funding of two 'extra-care' housing projects put forward by Housing and Health and Social Services Departments in May 2011<sup>97</sup>, which have replaced Longue Rue House and Maison Maraitaine residential care homes.

these expenses. Care costs, on the other hand, are hard for individuals to predict or plan for, and may be best met by the States.

The principle of separating costs in this way is one that is used in many other jurisdictions. In Scotland, for example, the government pays a universal grant towards ‘personal and nursing care’ for people living in care homes, but living and accommodation expenses are paid by the person in receipt of care if they can afford to do so<sup>98</sup>. In Jersey, the Long-term Care Insurance co-payment is based on accommodation and living costs, with Long-term Care Benefit intended only to cover the care element of the cost<sup>99</sup>. Both of these are relatively generous compared with England where only nursing care is paid for<sup>100</sup>.

The Working Party, therefore, believes that whilst the States should seek to continue to pay all or most of the care and support costs across all care settings (if possible), individuals could be asked to contribute more to cover their living and accommodation costs where these are being subsidised presently.

Since individuals living in the community or in extra care housing already cover their own living and accommodation costs, changing the system to align it with this principle would largely affect individuals living in care homes who are in receipt of Long-term Care Benefit and those paying a ‘long-stay fee’ in the Duchess of Kent, Lighthouse Wards or Mignot Hospital Continuing Care Ward.

Anyone who cannot meet the co-payment and anyone living in the community who cannot cover their accommodation and living costs can apply for means-tested assistance from Supplementary Benefit. However, any savings to the Long-term Care Insurance Scheme from increasing the co-payment to reflect individuals paying for their accommodation and living costs must clearly be reduced by an increase in Supplementary Benefit claims by those unable to afford to pay the increased cost.

#### **7.4.2 Applying the principle: increasing personal contributions towards bed-based care (Recommendations 9e and f)**

Significant work would need to be undertaken to apply the principle outlined above to the Long-term Care Insurance Scheme. This would include:

- Working in partnership with care providers to agree what falls into each cost category with a clear definition of what is covered by ‘care costs’ and what is not.
- Confirming and agreeing what accommodation and living costs reasonably cost.
- Identifying who the increased cost would affect and ensuring that they are informed and supported through the transition to a new charging system.

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<sup>98</sup>Scottish Government (2015) *Free Personal and Nursing Care*. Available at: <http://www.gov.scot/Topics/Health/Support-Social-Care/Support/Older-People/Free-Personal-Nursing-Care>.

<sup>99</sup> Jersey (2014) *Long-term care scheme: benefits*. Available at: <https://www.gov.je/Benefits/LongTermCare/Pages/LongTermCareBenefits.aspx>.

<sup>100</sup> NHS (2015) *What is NHS-funded nursing care?* Available at: <http://www.nhs.uk/chq/Pages/what-is-nhs-funded-nursing-care.aspx>.



a) *The current level of the Long-term Care co-payment*

At present the Long-term Care co-payment is specifically set so that it is lower than a full Old-age Pension. In 2016, for example, the co-payment has been set at £193.97 per week. Someone receiving a full-rate Old-age Pension from the States would receive £204.45 per week<sup>101</sup>. 82% of consultation respondents felt that it was important that the co-payment remained affordable within the full-rate Old-age Pension.

Whilst the Working Party understand why members of the public may be concerned about the prospect of having a co-payment larger than the pension, it is not felt realistic to subsidise accommodation and living costs in order to ensure that they are artificially lower than the Old-age Pension when people living in other settings pay more from their own personal resources:

- Many individuals who claim Long-term Care Benefit do not receive a full-rate Old age Pension: either because they have an incomplete contribution record (only 25% of claimants receive the full-rate pension, others receive a lower rate) or because they require care and support but are under pensionable age.
- If the only income someone receives is the full-rate old age pension at £204.45 per week (2016 rates) this amounts to approximately £905<sup>102</sup> per month. If living in the private rental sector this would be unlikely to cover in full rent, utilities and grocery expenses. Individuals would routinely need to supplement this by either use of savings; or the receipt of a private pension. The old-age pension may, therefore, only be sufficient income for someone who has additional income (from work, a private pension etc.), is a home-owner, or who lives in subsidised housing.

Good figures are not currently available on the actual cost of living and accommodation costs in care homes in Guernsey at present, but in 2015 the co-payment was £190.75 per week. By comparison, the Jersey co-payment (which is explicitly related to accommodation and living costs) was £312.75 per week. The charge for accommodation and living costs in the UK's proposed (and now postponed) care cost cap scheme was £12,000 a year, the equivalent of around £230 per week. Someone claiming supplementary benefit and rent allowance as a single householder in Guernsey could receive £377.24 per week in 2015. £190.75 per week, therefore, seems unrealistically low to cover living costs. For the purposes of the modelling undertaken below the Jersey figure has been used. Though this is somewhat lower than the income a single householder in Guernsey could receive, an individual's expenses in a care home are likely to be less than compared with the cost of living alone.

b) *Possible impact on Long-term Care Insurance Scheme*

Using the Jersey co-payment figure as a proxy, and combining this with the other assumptions referenced in Box A above, some projections were undertaken in order:

- (i) To show the impact on the Long-term Care Insurance Fund of transferring responsibility for accommodation and living expenses to individuals (as above);

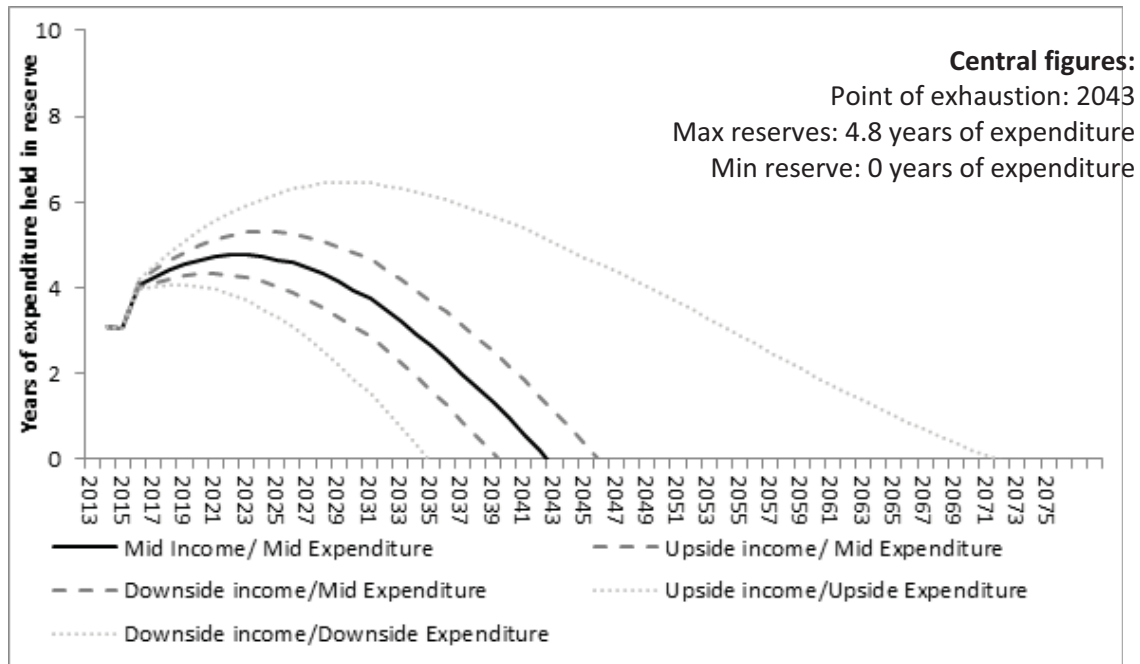
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<sup>101</sup> N.B. Only 25% of pensioners actually receive the full-rate pension. (Billet XVIII, 2015)

<sup>102</sup> (204.45/7)\*31.

- (ii) To examine the potential impact on contribution rates to the Fund; and
- (iii) To understand better the impact of these changes on Supplementary Benefit expenditure.

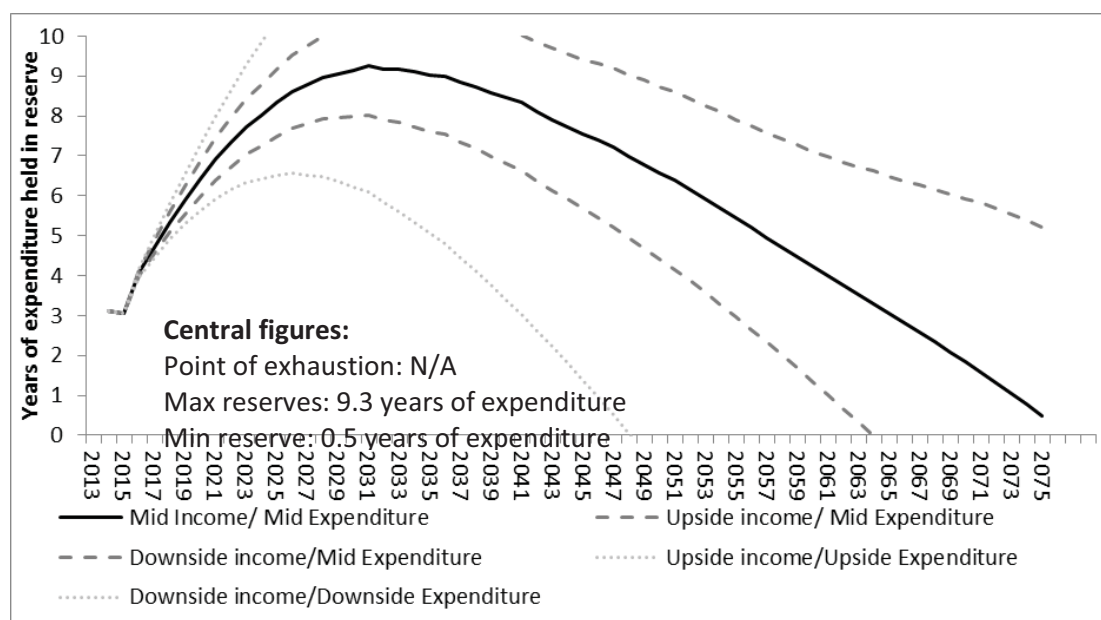
**Figure 7M: The impact of the Long-term Care Insurance Scheme paying for care costs only (i.e. applying the proxy figure for increasing personal contributions to £312 per week to reflect accommodation and living expenses), with there being no changes to the scope of services paid for by the Long-term Care Insurance Fund**



Applying the central projection, increasing the co-payment to £312 per week would extend the life of the Fund to 2043 – an increase of 12 years (see **figure 7I** above).

Of itself this would be insufficient to maintain the Long-term Care Insurance Fund on a long-term basis to meet the demographic challenges ahead; therefore, a combined approach has also been modelled which examines the possibility of increasing personal contributions to reflect accommodation and living expenses to £312 per week and increasing contributions by 0.5%.

**Figure 7N: The impact of the Long-term Care Insurance Fund paying for care costs only by increasing personal contributions to £312 per week to reflect accommodation and living expenses and increasing contribution rates by 0.5%**



**Figure 7N** shows that, using the central projection, these two measures together would be sufficient to extend the lifespan of the Long-term Care Insurance Fund to the end of the projected period of 60 years.

However, **this would be on the assumption that the Fund would remain limited in coverage to private sector residential and nursing home care only, whereas the Working Party considers that the scope of its coverage should be broadened** (see section 7.5 below).

*c) Possible impact on Supplementary Benefit*

Limiting expenditure from the Long-term Care Insurance Scheme to cover the care element only would reduce overall spending from the Fund but increase the amount paid by individuals, as they would be required to fund their living expenses and accommodation costs to a figure that would exceed the old-age pension. If they were unable to do this from their own resources, individuals would need to be able to claim assistance from Supplementary Benefit. At present, this is means tested and does not take into account property assets.

The percentage of individuals who, in 2014, could not meet the co-payment (£193.97 per week in 2016) from their own resources is as follows:

|                           |     |
|---------------------------|-----|
| Residential care          | 22% |
| Residential with EMI care | 18% |
| Nursing care              | 34% |

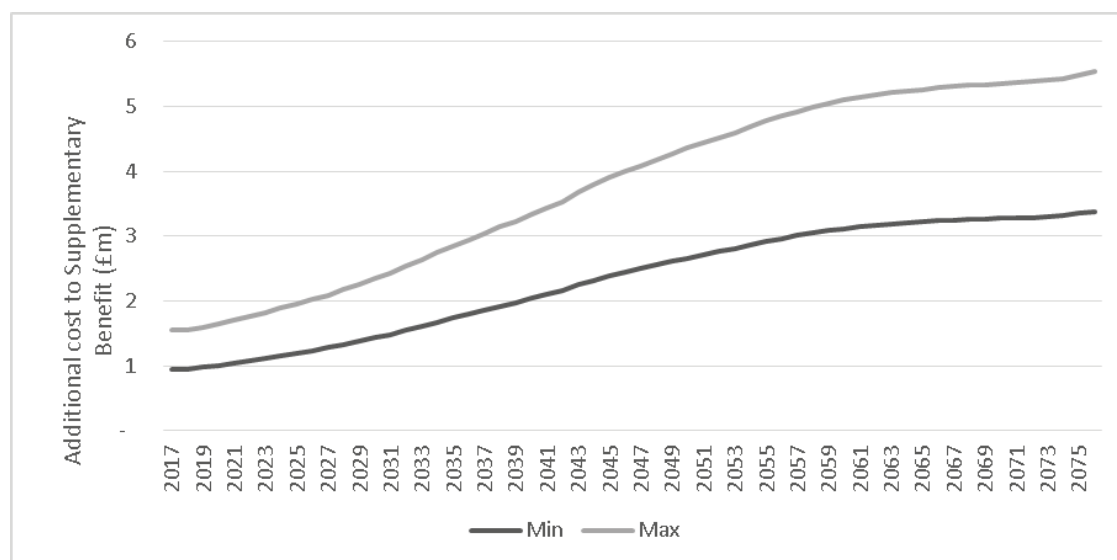
This means that more than one in five people living in residential care who receive a benefit from the Long-term Care Insurance Scheme also require assistance from Supplementary Benefit to meet the cost of the co-payment towards their care. This rises to a figure of one in three of those living in nursing care.

In financial terms, this equates to expenditure of circa £500,000<sup>103</sup>.

Therefore, asking individuals to contribute more towards their accommodation and living expenses will impact on Supplementary Benefit expenditure, which is funded by General Revenue. It will also increase the number of people requiring such assistance.

The value of the transferred cost is difficult to estimate accurately, being dependent on the income profile of future claimants. However, broad estimates are for an additional requirement of £1.0m to £1.5m per annum in Supplementary Benefit expenditure (see **figure 70**). This represents between 25% and 35% of the cost 'savings' in the Long-term Care Insurance Fund through removal of responsibility for meeting accommodation and living costs<sup>104</sup>.

**Figure 70: Estimated impact of increasing personal contributions to £312 per week to reflect accommodation and living expenses on supplementary benefit costs**



It should also be recognised that if more people are claiming Supplementary Benefit, then more people will be living on the 'personal allowance' rate of £30.37p.w. (discussed in section 7.2 above). If changes are made which will increase the number of individuals relying on the personal allowance, the opportunity should be taken to review whether this is an appropriate

<sup>103</sup> A further £1m of Supplementary Benefit is claimed by tenants living in extra care housing.

<sup>104</sup> NB. The above assumes that there are no above-inflation increases in the rates of Supplementary Benefit or the co-payment during this time.

amount to cover the personal expenses of those individuals who receive it and how this relates to other accommodation and living costs which an individual is asked to contribute towards.

#### **7.4.3. Summary**

Whilst there is a good case for the States to adopt some responsibility for helping individuals with the risk of unpredictable care costs, it would be possible to ask individuals to pay more towards their accommodation and living costs. Initial projections suggest that this would substantially increase the sustainability of the Long-term Care Insurance Scheme, though this would be somewhat offset by an increase in Supplementary Benefit claims. If property assets were included in means-testing this would mean that costs to Supplementary Benefit would increase less rapidly.

## 7.5 - Stage 3: Expanding the scope of the Long-term Care Insurance Scheme

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**Recommendation 7(h):** To agree, in principle, that the Long-term Care Insurance Scheme should be extended to cover care and support costs for people living in their own homes (including those accommodated in their own homes in sheltered and extra care housing).

**Recommendation 7(i):** To direct the Committee for Employment and Social Security, in conjunction with the Policy and Resources Committee, to investigate in detail the implications for contributors, individuals and for the States of the application of the principle that the Long-term Care Insurance Scheme should be extended to cover the cost of care and support at home, and to report to the States with its findings and recommendations no later than October 2018.

**Recommendation 7(j):** To agree that the investigation of this principle should include:

- a review of the role of related benefits such as Severe Disability Benefit and Carer's Allowance;
- detailed investigation into the possibility of personal budgets, including, if appropriate, the establishment of a pilot project to inform the research.

**Recommendation 7(k):** To note that any costs associated with the investigation of this principle will be met from the Long-term Care Insurance Fund.

**Recommendation 7(l):** To direct the Committee for Employment and Social Security to keep under review whether there is a strategic, long-term financial need to introduce: (i) the inclusion of capital assets in any means-testing of benefits associated with the provision of long-term care; and (ii) the capping of care costs to set out the respective funding liabilities for individuals and for the States.

At present the Long-term Care Insurance Scheme provides funding only to individuals receiving care in private and not-for-profit care homes. There are a number of reasons why it might be beneficial to the Strategy if the Fund was widened so that people could use it to receive care and support in their own homes:

- **Rationalisation and consistency** – expanding the scheme to allow the Fund to be used to pay for extra care housing and care at home may help to improve the consistency and equity of the whole system (which was discussed in 7.2.1 above).
- **Personalisation and choice** – key to the Strategy is the principle that individuals should receive person-centred services and be included in decisions made about their care. The current system does not necessarily support people to deploy the funding available in the most effective way to meet their own needs. Expanding the scheme so that it could support people to receive a wider range of services could allow for greater personalisation of services.
- **Expansion of the range of services and the number of providers of services** – private and not-for-profit providers of services are more likely to develop services if there is a clear indication from the States that there will be funding available to support people

to access those services. Allowing people to access services from a range of approved providers could encourage growth of community-based services and offer opportunities for providers to innovate into new forms of care which would be much less likely to happen in the current system.

- **Making opportunities to maintain independence more attractive** – making care at home easier to access through expanding the range of providers may encourage individuals to consider a full range of care options and maintain their independence rather than opting for higher dependency care than they need.

It is not anticipated that seeking to encourage the development of community care services in the private or third sector would ever completely replace services provided by HSSD. In particular, it does not make sense to pursue a market-based provision model for very specialist services where there is only enough demand for a single provider to provide the service. There is a risk that such privatisation could hold individuals in need of their service to ransom by creating a monopoly. In these circumstances it will be necessary to continue providing services within the public sector or via careful commissioning or contracting to a third party. However, if private and third sector care services do develop it may be possible to reduce the quantity of more generic services currently supplied by HSSD and thus reduce the cost burden on General Revenue.

This section explores the implications of pursuing the principle of expanding the scheme in four stages:

- Firstly, different options for expanding the scope of the Scheme are outlined.
- Secondly, there is an overview of some of the considerations that need to be given to the implications of broadening the Scheme for the balance of funding between the Long-term Care Insurance Scheme and General Revenue.
- Thirdly, the role of Severe Disability Benefit and Carer's Allowance is considered as part of this picture.
- Lastly, in light of increased cost to the Long-term Care Insurance Scheme, further measures to increase the sustainability of the Fund are considered, including the amount of capital assets in means testing.

### 7.5.1 Options for expanding the scope of the Scheme

There may be several different ways of approaching the expansion of the Long-Term Care Insurance Scheme to provide access to funding for alternative forms of care. In particular, it may be possible to expand the existing Scheme to include a wider range of providers of care and support services including supported housing providers, like the extra care schemes, and domiciliary care services.

Alternatively, it would be possible to introduce more significant changes and pursue 'personal budgets'. This may require a pilot project and substantial new legislation. It is possible that something like the former could be implemented as an intermediate stage towards the latter. Deciding how to approach the expansion of the Scheme will be a significant piece of work that will require further consideration.



Part of what should be considered during this process is whether or not there is a threshold point at which it becomes unaffordable to provide the level of care and support needed to someone within the community, and at which point extra care housing or a care home is the only feasible option. In many cases, if someone needs X hours of care a day, the costs should not be significantly different whether those X hours are received in their own home, in an extra care flat or in a care home. The staff costs of care will be similar. The difference in care-related costs will be to do largely with travel time and travel costs, with the possibility of costs associated with the suitability of the home environment for caring. Where care needs require specialist or nursing attention it may be the case that care can only be appropriately provided in certain settings. Whilst this does not prevent the possibility of giving people more choice about where they receive their care, thought does need to be given as to the appropriate limits placed on this choice.

*a) Adding 'approved providers' of domiciliary and extra care services to the existing scheme*

At present in Jersey individuals can be assessed as having one of four levels of care need. The amount of Long-term Care Benefit they receive is related to the level of need they have been assessed at, rather than where they receive care. They can then use this benefit either to help to fund a placement in a care home or with any of a list of 'approved providers' of care services (the list is managed by the Health and Social Care Department). This list includes private and not-for-profit providers of domiciliary care services to people in their own homes.<sup>105</sup>

Whilst this would require legal changes, it could build on the framework of the existing Scheme and may, therefore, be faster to introduce.

*b) Personal budgets*

Likely to require a more substantial departure from the existing Long-term Care Insurance Scheme, personal budgets could be an alternative option to explore.

In the UK and in many other countries, people with care and support needs are given more choice via '**personal budgets**'. A personal budget is an amount of money set aside by the government to meet someone's care and support needs. The amount of money they receive depends on the level of their need. People then have some choice about how to spend this money. There are a number of ways in which this can be done but these include:

- Managed personal budgets – where a social worker works with the person with care needs to identify what services they want to spend their personal budget on from a 'menu' of approved providers, and then arranges for these services to be paid for from the personal budget without the individual needing to contact care agencies themselves or handle the money. The level of

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<sup>105</sup> States of Jersey (2015) *About the long-term care scheme*. Available at: <http://www.gov.je/Benefits/LongTermCare/Pages/LongTermCareAbout.aspx>.

complexity of a managed personal budget could vary considerably – whilst something relatively basic like that described above in section a) could be implemented, there could be considerably greater room for variation in assessment and assigned budget levels for individuals.

- Direct payments – where a cash sum is given to a person with care or support needs to arrange their own care and support. This can include using the personal budget to hire carers directly. In this case the individual manages the care that they receive directly with the suppliers, keeps records of how the money is spent and, if employing directly rather than purchasing services, is responsible for complying with employment legislation.

Personal budgets are designed to support people to make choices about how they receive the care and support they require. Some of the challenges to making personal budgets work well in Guernsey and Alderney would be:

- Empowerment vs bureaucracy – personal budgets aim to empower people to make informed choices about what care services they wish to engage. The design of any personal budget system needs to balance the government's responsibilities to account for how public money has been spent and ensure that care services are safe, with an individual's freedom to engage the support that they want or need. There is a risk that a personal budget system could become overly bureaucratic.
- Cultural change – the social workers or other staff who help people to choose how to spend their personal budgets must respect the decisions of the people that they work with. If the approach taken is (unintentionally) paternalistic then staff may prevent people from accessing the services that they want.
- Creating a market – in Guernsey and Alderney at present there are very few private and third sector care providers who cater for people living in their own homes. If the funding system for care changed overnight, people might find that there was nothing for them to spend their personal budget on. If personal budgets are developed they might have to be introduced gradually.
- Specialist services – there are a lot of people who need general care and support so there is likely to be enough demand to support the development of a competitive market place with several suppliers. However, for those who need very specialist support this might not be the case, so providing for specialist support may require continued public service provision or careful consideration to ensure that people are not exploited by monopoly providers.
- Different outcomes for different groups – in the UK, people with physical disabilities have been found to have better outcomes from holding personal budgets than older people or people with learning disabilities. Research would need to be undertaken into why this has been the case as a prelude to their introduction in Guernsey and Alderney (if indeed personal budgets are pursued).

- Legal issues – if personal budgets are introduced a proper system of regulation will need to be established for home care (domiciliary) providers. If a ‘direct payments’ system is introduced where people can choose to employ their own carers directly then there will need to be advice and support on people’s legal obligations as employers.

It is worth noting that, whilst personal budgets have been pursued in the UK in the belief that they would be more cost-effective, existing evidence on cost savings is not yet clear and in many cases it seems that personal budgets have not resulted in significant savings being made<sup>106</sup>. It seems that if personal budgets are pursued in Guernsey and Alderney, it should not be on the basis that they will save a lot of money, but because other non-financial benefits will accrue and contribute towards the wider objectives of the Strategy in terms of providing person-centred services and encouraging innovation and partnership with the private and third sectors.

Mixed views were expressed in the feedback received from the public consultation process, ranging from those who expressed a strong desire to see the introduction of personal budgets as a means of empowering individuals to have more choice about the care they receive, to those who felt that a system of personal budgets would need to be carefully overseen and might be difficult for some people with a care and support needs to manage<sup>107</sup>.

Personal budgets could significantly enhance the opportunities of some adults to tailor their care to meet their needs and to allow them to have some degree of control over their lives, in particular, and participate in the community. This could revolutionise the way that disabled adults are supported. However, the implications of introducing personal budgets in Guernsey and Alderney are not clear. It is recommended, therefore, that the possibility of operating a pilot for personal budgets be explored.

Before the expansion of the Scheme is pursued some thought also needs to be given as to whether to take an ‘approved providers’ approach or to pursue the potential of Personal Budgets as managed budgets or direct payments. In the public consultation, 79% of respondents felt that a grant or benefit should be made available to fund care from private and third sector care providers in people’s own homes. There were a range of views on the efficacy of personal budgets.

## **7.5.2 The balance between the Long-term Care Insurance Fund and General Revenue**

The expansion of the Long-term Care Insurance Scheme to allow people to use the Fund to purchase care in supported housing and community care will increase the demand on the Long-term Care Insurance Fund, but should also reduce the demand on General Revenue

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<sup>106</sup> See for example Audit Commission (2010) “Financial management of personal budgets – Challenges and opportunities for councils” p.2. [Online]. Available at: <http://archive.audit-commission.gov.uk/auditcommission/sitecollectiondocuments/AuditCommissionReports/NationalStudies/20101028financialimplicationsofpersonalbudgetssummary.pdf> [accessed 8th May 2015].

<sup>107</sup> Questions 46 and 47 of the consultation process also related to personal budgets and direct payments. See Appendix D.

funded services. Thought will need to be given as to how to rebalance funds between General Revenue and the Long-term Care Insurance Fund.

The following, in particular, require consideration:

- Whether a grant from General Revenue is required in order for the Fund to be able to bear increased costs. For example, if extra care housing is paid for from the Fund, the money currently used to pay for extra care housing is part of Housing and HSSD's existing budgets from General Revenue and could, instead, be transferred to the Fund annually.
- Whether it would be desirable for there to be an increased proportion of cost coming from the Long-term Care Insurance Fund since the Fund can be used to 'save' money to cushion future increases in expenditure, whereas General Revenue can generally only be used to pay for costs within the calendar year it is raised. Having a higher proportion of costs funded from the Long-term Care Insurance Fund could, therefore, distribute cost more evenly across a time period.
- Whether, in light of changes, all HSSD services will continue to be General Revenue funded, or if it would be more appropriate for some community services to be funded via the Scheme.
- Further review of sustainability issues: see 7.5.4 below.

Consequently, some modelling and projection work would need to be undertaken to determine what implications the transfer of service funding would have; whether a Revenue grant should be pursued; and to what extent the transfer could mitigate against the increasing costs anticipated within General Revenue funded services.

### **7.5.3 Severe Disability Benefit and Carer's Allowance**

The purpose of Severe Disability Benefit and Carer's Allowance need to be considered within the context of changes to the funding and provision of services.

#### *a) Carer's Allowance*

Many people care for and support their family members or friends. In some cases this can be an intensive commitment and some people give up work in order to be able to provide care.

The only financial compensation to carers at present is Carer's Allowance, which provides a small cash benefit (2016: £81.28 per week) to carers who care for someone who is severely disabled for more than 35 hours per week. Whether or not Carer's Allowance should change is closely related to whether personal budgets are adopted in Guernsey. In some countries personal budgets can be used to employ or pay a family member to provide care. How personal budgets relate to carers will need to be carefully considered if they are pursued.

The consultation asked whether, if personal budgets were introduced, respondents would support or oppose the use of personal budgets to pay family members who are carers for the caring they undertake. 74% were in favour of doing so.

Decisions need to be made as to the role and purpose of Carer's Allowance; whether it is intended to compensate individuals fully for the caring work that they undertake and how this relates to other forms of funding.

*b) Severe Disability Benefit*

Many people with disabilities have higher living costs than an average person since they may have higher transport costs, or may have costs associated with dietary supplements, heating or prescription costs. **Severe Disability Benefit (SDB)**<sup>108</sup>, to some extent, offers some compensation for additional costs associated with disability. However, it is also used to purchase care services and therapy. If personal budgets for care services were introduced in Guernsey thought would need to be given to how SDB would fit with such a system, and if the purpose of SDB and Personal Budgets would overlap.

In the UK the closest equivalent to SDB is a 'Personal Independence Payment'. This is not primarily paid to meet care costs, which is relevant as it is known that existing claimants of SDB in Guernsey use it to pay for a range of items not only for care.

Between May 2014 and January 2015, 53 claimants of SDB returned an anonymous questionnaire included with their SDB claim packs which included a question on what the benefit would be spent on.

| Item of Expenditure | Number of responses |
|---------------------|---------------------|
| Personal/Social     | 12                  |
| Domestic            | 46                  |
| - Food              | 19                  |
| - Housekeeping      | 19                  |
| - Maintenance       | 8                   |
| Emergency Help      | 10                  |
| Transport           | 33                  |
| Care                | 41                  |
| - Day care          | 13                  |
| - Personal care     | 23                  |
| - Nursing care      | 5                   |
| Equipment           | 20                  |
| Medical             | 38                  |
| - Therapy           | 12                  |
| - Medication        | 13                  |
| - Treatment         | 13                  |
| Other               | 17                  |

<sup>108</sup> Further information about Severe Disability Benefit is provided in Section 2.

If Personal Budgets were introduced to cover care costs, it may be that some thought would need to be given as to how to develop SDB to preserve its value to assist with costs other than care. The UK Personal Independence Payment, for example, has two significant features that the SDB Benefit does not<sup>109</sup>:

- Firstly, it is split into two components which are assessed separately –
  - one is intended to be related to additional costs associated with a **mobility impairment**. This could, for example, include extra transport costs for someone who cannot easily walk, drive or take public transport;
  - the other part is to do with costs for a disabled person associated with **Daily Living**. This could include additional costs for food, heating, incontinence pads etc.

This means that someone could claim for one of these elements if, for example, they do not have additional day-to-day living costs but have significant difficulty getting around - they could receive a small amount to contribute towards meeting their mobility needs.

- Secondly, the Personal Independence Payment has a lower rate payable to people with less severe conditions. Currently the threshold for claiming SDB is quite high (as the title might suggest) and there is no lower level for people with lower needs.

The Personal Independence Payment is separate to (though related to) personal budgets. There was a strong desire expressed by one respondent in the consultation that SDB not be absorbed into personal budgets entirely, but that it should have a distinct role.

76% of consultation respondents agreed that SDB should be reviewed and reconfigured so that it is accessible in smaller amounts to people with less severe disabilities. 83% agreed that SDB should be calculated separately for costs associated with mobility and for costs associated with increased living costs associated with having a disability.

There should be clarity going forward about the role of SDB and to what extent this has a separate purpose, and is distinct from a payment to provide care and support. Any such review should include consultation with those currently in receipt of SDB and Carer's Allowance.

#### 7.5.4 Further consideration of sustainability

Reconfiguring services and funding should help to reduce costs in the long-term. However, as explained above in section 7.2, increasing demand is expected to increase costs, and whilst the changes proposed in 7.3 and 7.4 above will stabilise the part of the system currently funded

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<sup>109</sup> <https://www.gov.uk/pip/what-youll-get>

from the Long-term Care Insurance Fund there remains the challenge of addressing rising costs in services which are currently funded via General Revenue.

Increases in taxation may be one option to consider, but there will be a limit on the extent to which this can be pursued.

Further ways of controlling costs may also have to be considered. Inevitably these mean asking individuals who can afford to pay more to do so. Options already identified include:

- a) The introduction of cost caps
- b) The inclusion of property assets in means testing

Consideration has also been given to:

- c) Making family members financially responsible.

But for a number of reasons it is not recommended that c) is pursued.

*a) Care cost caps*

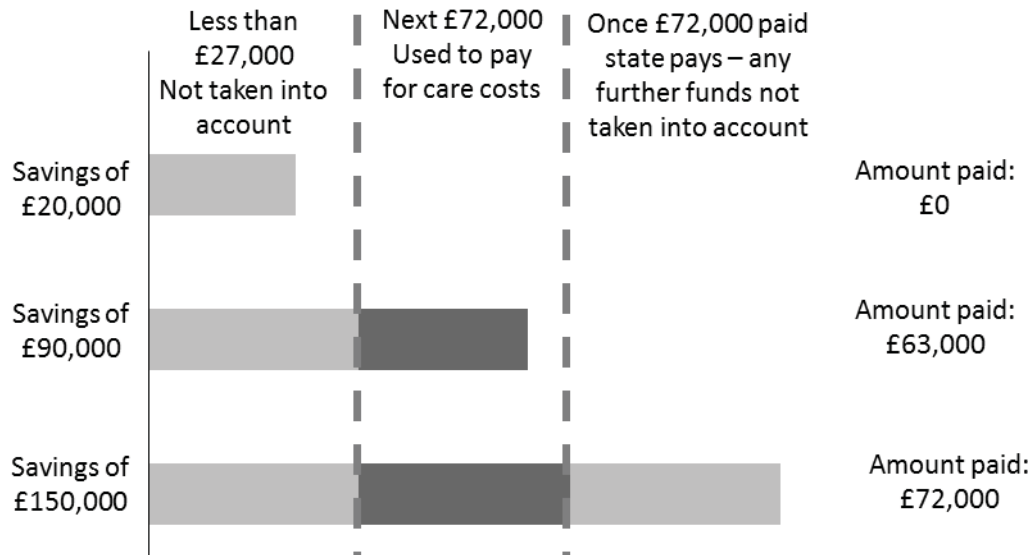
Even if individuals meet their accommodation and living costs in full, it is possible that there still may not be enough public funding to cover care costs. If this is the case then it may be possible to use 'care caps' to limit the amount that individuals are asked to contribute to their care (wherever they receive it).

To protect those people that may require care and support for many years and those who do not have the resources to pay for care, some governments have established thresholds to establish the parameters for state funding (see **figure 7P** below). Typically these take the form of:

- A lower threshold, under which people are thought not to be able to afford to pay their care costs. For example, a government might undertake to pay the costs of anyone with assets of less than £20,000. People who have slightly more than this (say £30,000) would be expected to pay their way until their resources were lower than this threshold, i.e. they would need to spend £10,000 on their own care and support before the government would start paying.
- An upper threshold or 'cap' so that once people have paid a certain amount of money towards their care costs they are not asked to pay more and care is paid for exclusively by the government.

**Figure 7P – Operating a care cost cap**

- **Illustrative example** – actual thresholds would need to be further considered (based on UK figures for non-home owner over lifetime)



The UK has looked into introducing such arrangements but has deferred this until 2020 due to the current funding pressures on social care provision.

In Jersey, a cost cap system was introduced as part of the reform of its Long-term Care Scheme in 2014. The lower threshold for receiving help is £419,000; anyone who has wealth over this amount is expected to pay up to a cost of £52,120<sup>110</sup>. This effectively provides some protection of modest property assets.

Where thresholds are set has a significant impact on which parts of the population are most affected by a cap system.

A system which 'caps' care costs could control overall long-term expenditure by the States. It would also allow people to be able to begin to plan for meeting long-term care costs, whereas, without the cap, the cost is an unknown quantity and difficult to plan for.

However, the Working Party acknowledges that the introduction of such a system in Guernsey and Alderney would not be without controversy given that currently care and support costs are almost exclusively paid for by the States, irrespective of whether an individual lives at home, in extra care housing, or in a care home.

<sup>110</sup> States of Jersey (2014) "Long-term care scheme: benefits". (Online) Available at: <http://www.gov.je/Benefits/LongTermCare/Pages/LongTermCareBenefits.aspx> (accessed 18th May 2015)



There are also equity arguments: such a system invariably protects wealthier older people who have significantly more than the cap in assets, whilst requiring those with moderate savings or assets to spend until they reach the lower threshold.

Nonetheless, if the affordability of the care system really does become an issue, introducing a threshold for care cost contributions is an option that the Working Party believes should be given further consideration and, therefore, it should be kept under review.

*b) Including assets in means testing*

The issue of means-testing personal assets was particularly controversial during the consultation period, with many respondents to the survey expressing dissatisfaction about the suggestion that personal assets - in particular, the family home – could be taken into account when considering whether someone is able to afford to contribute more towards their personal care costs.

At present, under the Long-term Care Insurance Scheme, if people do not receive a full pension and cannot afford to pay the co-payment for their care home placement or long-stay hospital fees they can receive support from Supplementary Benefit. This assistance is means-tested, which means that the Social Security Department obtains information about the individual's resources in order to determine whether they are eligible for support to meet the cost of the co-payment. Under this assessment, the value of the 'family home' is not taken into account, even if the individual is not living there. For example, if someone living in a care home has very little income or money in the bank, but owns an empty property worth £500,000 they will receive support (using General Revenue funds raised through taxation) and will not be obliged to sell or rent out the property.

This is because, as described above, the Long-term Care Insurance Scheme was implemented with an implicit commitment that people would not be forced to sell the family home to pay for long-term residential or nursing care.

Whether or not houses are included in means test assessments by Social Security will become increasingly significant if the amount that people are being asked to contribute to their care increases.

If the co-payment is increased to cover living and accommodation costs, as suggested in 7.3 above, then the number of people claiming Supplementary Benefit to cover this cost will also increase. Including the value of property in the means test would mitigate this increased cost to Supplementary Benefit by taking into account the value of non-cash assets, like property, making available funding from those who are asset-rich and cash-poor. Whilst the data is not currently available to determine how much difference this would make, it has the potential to extend the life of the Fund significantly and to reduce the need for increases in contributions. Though this would increase the sustainability of the Fund, it would not be popular with the public.

If proposals were put forward to incorporate property assets in means testing the following considerations would apply:

(i) *Arguments for including houses in means testing*

Aside from the key financial mitigation that including housing in means testing would offer, there are other arguments for including houses in means testing:

- At present, some individuals moving into a care home already sell their properties, and either invest the funds from their house sale, or use it to pay 'top up' fees towards the cost of their care. Others let their properties and use the rental income to pay care home 'top up' fees. It should also be noted that, as a matter of policy, property owners moving into a GHA extra-care scheme (i.e. at La Nouvelle Maraitaine or Le Grand Courtil) are required to purchase a partial ownership flat<sup>111</sup>, which, although the care provided is 'free' (i.e. paid for by the States) it may involve them selling or renting out the property to pay their accommodation and living costs.
- It could be argued that it is unfair to increase tax or Social Security contribution rates across the entire Island populations to fund the living costs of those who could afford to pay their own way. Since the Long-term Care Insurance Scheme was introduced, more Islanders are now living in rented accommodation due to an inability to purchase their own home. Such Islanders may well be increasingly unsympathetic to being asked to contribute, through their Social Security contributions and general taxation, to protect the property assets of others, especially when increases in contribution rates erode disposable incomes that are already under pressure. In addition, due to property price inflation, with properties now worth multiple times what may have been paid for them thirty years ago, claims that the value of property was 'earned' are only partially true as the increased value of the property is also related to fortunate timing of purchase. The following quotation from a respondent to the consultation process makes this point:

*"I very much strongly think that it would be unfair for people not to have to sell their own homes for care. As a younger person I know I will be working longer to pay for the elderly now than they themselves did. At least until I'm 70. I will also be paying more of my tax money to keep them as they live longer and due to the worsening dependency ratio."*

- Some have argued that protecting property in this way merely defends the inheritance of those who have parents who could afford to purchase property, potentially harming social mobility by protecting family wealth.

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<sup>111</sup> There are no flats for outright purchase at these schemes.

- Whilst most respondents were against using property in house sales, it is also true that most respondents were over the age of 55 and are more likely to gain personally in the foreseeable future from the continuation of such a policy.

(ii) *Arguments against including houses in means testing*

Many of the consultation respondents were adamantly against the use of property value in means testing. When asked the following question, ‘do you think that the value of houses should be taken into account in means-tests when people apply for financial support from the States to cover care costs?’ over half of respondents (59%) felt that people should not be expected to use the value of their house to contribute towards their costs.

One respondent to the public consultation document summed up a common public feeling as follows:

*“I do not believe it is fair that people work and save hard all their life and then have it taken away from them in old age. People who can never afford their own home and rely on the state would possibly still receive all the benefits. This is simply not fair.”*

(iii) *Other considerations*

If the value of the property in a means-test is to be incorporated at a future date the following should be considered:

- Whether the States or another funder could provide loans to meet long-term care costs secured against the value of a property, the loan being repaid upon the death of the person receiving long-term care.
- The need to manage the risk that people will give away their property to avoid being used in any assessment of the costs they should pay from their own resources. (In Jersey, if someone is seeking to claim from the Long-term Care Scheme, property assets which have been transferred in ownership in the ten years preceding a claim will be taken into account<sup>112</sup>.)
- The need to make sure that any scheme is fair to dependents or spouses who might still live in the property. In England, for example, the value of a house is not taken into account if a spouse/partner or dependent has lived in the house as their main or only home since before the individual with care needs moved into residential care.<sup>113</sup>

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<sup>112</sup> For more about the Jersey Scheme see:

<http://www.gov.je/Benefits/LongTermCare/Pages/LongTermCareAbout.aspx>.

<sup>113</sup> For more information on the English system see Age UK (2015) Factsheet 38 “Treatment of property in the means test for permanent care home provision : [http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS38\\_Treatment\\_of\\_property\\_in\\_the\\_means-test\\_for\\_permanent\\_care\\_home\\_provision\\_fcs.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS38_Treatment_of_property_in_the_means-test_for_permanent_care_home_provision_fcs.pdf?dtrk=true).

*(iv) Conclusion – including the value of houses in means testing*

The Working Party acknowledges the potential benefits of asking individuals – where they can afford to do so – to contribute more towards their care and support.

Whilst it is a step too far to recommend introduction of the inclusion of housing in means testing at this time, the Working Party considers that this may become necessary in the future to prevent cost escalation and, therefore, should be kept under review as part of further investigations. Evidence should be gathered to determine what effect including housing in means-testing would have on the Long-term Care Insurance Fund.

*c) Family responsibility for costs*

In grappling with the complex issues associated with developing a more sustainable model for funding long-term care, there is a need to ensure that any such system balances the relative contributions of the individual needing care and the state (i.e. the community via taxation or social security contributions).

The Working Party also acknowledges that there can be varying views about the responsibility of family members to pay for care. In Guernsey, at present, family members, other than a spouse or partner, are not held legally responsible for their family members' care. Many families voluntarily contribute significant amounts of their time and, in some cases, money, towards the care of their family members. Other people, for a variety of reasons, are not emotionally or geographically connected to their relatives in such a way that this kind of support feels appropriate to them.

The Working Party has considered the extent to which family members should be held responsible for providing for the care needs of adult family members and whether the existing arrangement is culturally appropriate in Guernsey. There are a number of reasons why holding family members responsible for care needs may not be appropriate in Guernsey:

- Being held responsible or financially responsible might increase the number of people unwillingly becoming informal carers. Being an informal carer can be a substantial and difficult commitment and if people feel that they have been forced to be carers they may feel resentful, resulting in a poor quality relationship between the individual and the cared for individual.
- People with care and support needs may be humiliated or embarrassed by the thought of becoming, as an adult, a burden (financial or otherwise) on their parents or children. This feeling may be present even when family members voluntarily provide care, but could be even more humiliating if they do not wish but are obliged to provide care.
- Family structures are becoming less straightforward due to the prevalence of divorce, reconstitution of families, and geographical separation. The people whom an individual feels most appropriately to have played a parental role in

their life or to have been like a son or daughter may not be a blood relation but could easily be a step-parent or a partner's children. Identifying where responsibility is due could arguably be better left to the discretion of the individual rather than through the blunt instrument of identifying genetic links.

- Administering and enforcing a system in which family members were legally responsible, particularly where they live in other jurisdictions, may not be feasible even if the principle were looked on favourably. We know that there have been difficulties pursuing child maintenance from parents in some cases, and the outcome is likely to be analogous.
- At present Supplementary Benefit supports some people under the age of 18, even where their parents are in the Island. Arguably, if the principle of family support is not applied to those aged under 18 years, there is a weak precedent for applying it to adults with care and support needs.

This said, as we have previously seen in section 6, the contribution of family members who are informal carers at present amounts to millions of pounds worth of care. At its best family-based support can be some of the most effective care available.

Encouraging strong family bonds and providing better support for informal carers should, therefore, be core to the Strategy.

On this assessment, the Working Party concluded that it seems most appropriate to continue as previously and not to oblige anyone legally to provide care, or finances for care, for their parent or adult child.

In support of this view, a large majority of respondents who answered the question - 75% - disagreed or strongly disagreed that family members, other than a spouse or partner, should be financially responsible for a person's long-term care costs.

### **7.5.5 Summary**

The current funding system is neither consistent nor sustainable. It does not support individual choice about where to receive care. Changes should be made swiftly to extend the life of the Long-term Care Insurance Fund to help to prepare for the future. This will require an increase in the co-payment paid by individuals to reflect their accommodation and living costs and also a small increase in contributions.

Further work then needs to be undertaken to review the possibility of expanding the Scheme to allow for people to use Long-term Care Benefit to purchase other kinds of support including in supported housing contexts and community services. By drawing further services into the Scheme this will increase the proportion of services being funded by the Long-term Care Insurance Scheme rather than General Revenue. Consideration needs to be given to the balance between the two funding streams, how they relate to each other, and whether further measures need to be taken to increase the sustainability of the system either by further increasing the available public funding or through increasing personal contributions by including property assets in means testing only, or by introducing a cost-cap system.

## Appendix A - Glossary of Terms

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| <b>2020 vision</b>                  | The HSSD's '2020 Vision' was debated and approved by the States in May 2011 and set out a framework for future development of the health and social care system in Guernsey and Alderney.  |
| <b>Access</b>                       | The extent to which people are able to receive the information, service of care they need and are not discouraged from seeking help. Issues involved include distance of travel; physical access (e.g. premises suitable for people with limited mobility); communication (e.g. information in large print and other formats); and the provision of culturally appropriate service.  |
| <b>Accessible housing</b>           | Housing which has been specially adapted for someone with an impairment (e.g. limited mobility, autism or others).   |
| <b>Active support</b>               | A way of delivering care which is intended to: <ul style="list-style-type: none"> <li>· Provide 'real' activities at home and in the community</li> <li>· Organise support to maximise involvement</li> <li>· Train staff to develop an enabling style of support</li> <li>· Monitor improvements in practice</li> </ul>   |
| <b>Activities of Daily Living</b>   | Day-to-day tasks associated with the process of performing personal and domestic care, e.g. washing, bathing, dressing, hair and skin care, eating and drinking, and other basic daily tasks, such as cleaning.  |
| <b>Acute Care</b>                   | <p>Acute care is where people receive specialised support in an emergency or following referral for surgery or medical assessment, complex tests or other things that cannot be done in the community.</p> <p>The term 'acute care' arose when people used to go through the acute or emergency phase of their condition in hospital before moving on to community settings. Now the terms acute care, secondary care and hospital care are sometimes used interchangeably for services that are carried out by specialised staff and equipment. Acute care usually provides treatment for a short period, until the person is well enough to be supported in the community again.</p> |
| <b>Ageing demographic</b>           | Describes the situation in which the proportion of older people in the population is increasing over time.   |
| <b>Ageing Well in the Bailiwick</b> | Ageing Well in the Bailiwick is a group brought together by the Guernsey Community Foundation which consists of representatives from organisations working with older people, from the private, voluntary and public sectors.  |

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| <b>Ageism</b>               | Where unspoken assumptions and stereotypes based on a person's age are used to make judgements about what the person wants or needs without seeing them as individuals with diverse interests.   |
| <b>Aids and Adaptations</b> | Equipment or adjustments to a person's home to enable them to care for themselves and go about their day-to-day lives without support from another person. This may refer to physical adaptations to a property, or the introduction of equipment or assistive technology to support people to live independently.   |
| <b>Approved provider</b>    | <p>Under the Long-term Care Insurance Law (2002) the Administrator of Social Security may designate: "any provider of long-term care services as an approved care provider" and "any establishment as an approved care establishment" regulations can be made specifying registration process and quality standards to be met by any establishment wishing to be designated as such. This can be a requirement for an approved provider or establishment wishing to receive Long-term Care Benefit on behalf of a resident.</p> <p>In Jersey, a list of approved providers of care services is maintained by the Health and Social Care Department which can cover domiciliary services as well as residential services.</p> |
| <b>Assessment</b>           | The overall process for identifying and recording the health care and social care risks and needs of an individual and evaluating their impact on daily living and quality of life, so that appropriate action can be planned.   |
| <b>Assistive Technology</b> | Technology which can support and enable people to participate – this can include, for example, technology to assist with sensory impairments, such as hearing aids; equipment and adaptations to assist with mobility issues; technology which can assist with communication; technology to help people to remember to take medication; and so on. See also <b>telecare</b> and <b>telehealth</b> .  |
| <b>Avoidable Admission</b>  | Admission to hospital that would be unnecessary if alternative services were available.  |
| <b>Baby boomer</b>          | Refers to a generation of people born between the end of WWII and the mid-late 1960s.  |
| <b>Care and Support</b>     | Any support that a person might need in order to maintain their well-being. Help with transport, housework, paperwork, food preparation, personal care (e.g. bathing, eating or getting out of bed in the morning), help to go out, or someone to talk to.   |
| <b>Care community</b>       | The network of families, friends, community organisations, not-for-profit and private sector organisations and States-run services which provide   |

care and support to Islanders.

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| <b>Care continuum</b>                          | The range of services available which are intended to meet low to high need levels and their connection to each other. For services to be a 'continuum' then a person using services should experience smooth transition as they come into contact with new services which adapt around their changing needs.   |
| <b>Care coordination</b>                       | Working with an individual to identify what they need, what services are on offer and how best to arrange them to meet the needs of the individual.   |
| <b>Care Package</b>                            | The particular set of services, which may be provided by different providers, to be delivered to an individual. This might include a timetabled range of visits of different kinds of care professional to an individual throughout the week.   |
| <b>Care Pathway</b>                            | An outline (usually documented) of what stages of care a person can expect to go through according to the condition that they present with. This will show clearly the different organisations and services and individual will come into contact with, when and how the referrals between the services will work.  |
| <b>Care Plan</b>                               | A personalised care plan outlines the high level needs of an individual and documents the services to be provided, the assessed individuals and their carer(s) participation, the objectives, a review date, and consent from the assessed person to share the plan with the care team.   |
| <b>Care sector</b>                             | All of the organisations which provide care and support services for the exchange of public, charitable or private funding (whether or not profit based).   |
| <b>Care settings</b>                           | The type of place where an individual receives care e.g. hospital, care home, or in their own home.   |
| <b>Carer</b>                                   | A person who cares for or supports a family member or friend with a health condition.   |
| <b>Carer's Allowance</b>                       | Carer's Allowance is a weekly benefit intended for anyone who stays home to care for someone who claims Severe Disability Benefit because they need a lot of attention or supervision by day or night.  |
| <b>Children and Young People's Plan (CYPP)</b> | A plan which is reviewed periodically, setting out the objectives and actions required to ensure that there is a holistic and co-ordinated strategy for all children's services in Guernsey. This will enable the States of Guernsey, and its policy and delivery partners in the third sector, to prioritise how resources should be used, and will bring together all the organisations working with young people in schools and in the |



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|  | community, enabling them to work to a common agreed strategy.  |
| <b>Clinical Nurse Specialist</b>               | A nurse who is highly trained in a certain area of practice or in supporting people with a particular condition or group of conditions.  |
| <b>Commissioning</b>                           | A set of procurement processes used to tender or contract for a service provided by a third party. Commissioning tends to take a more outcome-focused approach than other forms of procurement, encouraging providers to innovate in how they deliver those outcomes.  |
| <b>Community Care</b>                          | Community care services provide health and social care to people in their own homes who have long-term conditions and require regular support (this can be a mix of medical support from nurses, for example managing medication or changing dressings, and social care support to help with personal care, for example, getting out of bed in the morning). |
| <b>Community Health and Wellbeing Services</b> | A group of services provided by HSSD which incorporates community nursing, senior carers, home helps, the shopping service and handy-person service, the health visitor for older people, social workers, and occupational therapists.   |
| <b>Community Mental Health Team</b>            | Multi-disciplinary team made up of psychiatrists, social workers, community psychiatric nurses, psychologists and therapists. Provides assessment, treatment and care in the community, rather than in hospitals, for people with severe and/or long-term mental health problems.  |
| <b>Community Nursing</b>                       | Nursing care (i.e. including medication, dressings and other medical tasks over and above help with day-to-day tasks) provided by qualified nursing staff who visit people living in their own homes in the community.   |
| <b>Co-morbidity</b>                            | Where a person has several different long-term conditions at the same time. For example, diabetes and a heart condition.   |
| <b>Co-payment</b>                              | At present, when someone moves into a care home and claims Long-term Care Benefit they are required to pay a 'co-payment' which is a contribution towards the cost of care from their personal finances. See section 7.2.1.  |
| <b>Corporate Housing Programme</b>             | The States Corporate Housing Programme (CHP) is an action plan of housing-related projects being carried out by States' departments, voluntary organisations and the private sector. The CHP is an important part of the Social Policy Plan.   |
| <b>Courtil Jacques</b>                         | Courtil Jacques is a sheltered housing development which is in proximity to and supported by staff from Le Grand Courtil extra care housing development in St Martins.   |

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| <b>Day Centres and Day Services</b>      | Facilities run by social services, health, or a voluntary organisation, that provides care, stimulations and activities. Presently, this is largely for people who live on their own or with family in the community. This can be a form of 'short-break' service   |
| <b>Dementia</b>                          | Term used for different illnesses that affect the brain and diminish the ability to do everyday tasks. 'Dementia' should be used to describe symptoms, not the condition itself. Symptoms include loss of memory; difficulty in understanding people and find the right words; difficulty in completing simple tasks and solving minor problems; mood changes and emotional upsets. |
| <b>Demographic</b>                       | Relating to the make-up of the population. In this context largely to do with the relative size of different age groups within the population.  |
| <b>Dependency</b>                        | Describes how reliant a person is on someone else for help with activities of daily living or for medical support – low dependency means not very reliant, high dependency means very reliant.  |
| <b>Dependency ratio</b>                  | The proportion of a population who are economically dependent - those who are eligible for retirement (over pensionable age) and those who are still in compulsory full-time education (children under compulsory school leaving age) - when compared to the number of people who are of working age (i.e. at present this is all those between the ages of 16 and 64 years).       |
| <b>Dignity</b>                           | Ensuring that a person receives the type of care that makes them feel respected as an individual and help them develop and maintain self-esteem.  |
| <b>Direct Payment</b>                    | A form of <b>personal budgets</b> where a cash sum is given to a person with care or support needs to arrange their own care and support.   |
| <b>Disability</b>                        | "Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" - UN Convention on the Rights of Persons with Disabilities.  |
| <b>Disability and Inclusion Strategy</b> | In November 2013, the States considered and approved the <b>Disability and Inclusion Strategy</b> <sup>114</sup> . The Strategy aims to improve the quality of life of disabled Islanders and carers so that they can be actively engaged socially, economically and culturally and that there are improved attitudes towards disabled people.                                      |
| <b>Disability Needs</b>                  | A survey undertaken in 2012 to inform the Disability and Inclusion  |

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<sup>114</sup> Policy Council – '*Disability and Inclusion Strategy*' – Billet d'État XXII 2013.

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| <b>Survey</b>                                  | Strategy. Available at: <a href="http://www.gov.gg/disabilitystrategy">http://www.gov.gg/disabilitystrategy</a> .  |
| <b>Domiciliary Care</b>                        | Assistance provided to a person in their home, including home care, equipment and adaptation, and meals on wheels. Are generally used to describe visiting services provided to help someone with activities of daily living (bathing, dressing, help with toileting, meal preparation, house cleaning, laundry etc.) (See 'Aids and Adaptations').  |
| <b>Duchess of Kent</b>                         | States-provided residential care for older adults with mental health conditions, particularly dementia.  |
| <b>Elderly Mental Infirmary (EMI)</b>          | Elderly Mental Infirmary (EMI) refers to older adults with a mental health condition, usually dementia. It is a category of Long-term Care Benefit which is higher than residential care to account for the extra care-work involved in caring for an individual with more complex support needs associated with dementia.   |
| <b>Enabling environments</b>                   | Housing, work or other built environments which are designed in such a way as to support people with impairments to be able to function without assistance – for example wheelchair accessible housing.  |
| <b>Enduring care and support needs</b>         | Where someone requires care and support on a permanent or ongoing intermittent basis. This is usually due to a long-term condition which could be a physical or learning disability, a mental health condition, dementia, chronic illness, conditions associated with ageing or due to another cause.  |
| <b>'Extra-Care' Housing</b>                    | Independent housing units (flats generally) where an on-site care team provides 24/7 care services to assist with activities of daily living. 'Extra care' housing schemes may also provide outreach care (see <b>outreach services</b> ) or support services into the surrounding community and may be a base for community facilities such as restaurants, hairdressers, etc.  |
| <b>Fiscal Framework</b>                        | The Fiscal Framework is a set of parameters agreed by the States in 2009 to guide future States fiscal policy (i.e. how much tax, borrowing etc. is permissible for the government), committing the States to long-term financial balance and limiting the size of the public sector.  |
| <b>Funding of Long-term Care Working Party</b> | The ' <b>Funding of Long-Term Care Working Party</b> ' was formed in mid-2011 and was active until the end of the States Term in April 2012 to examine the wide ranging and complex issues surrounding the funding of long-term care. It was formed in response to the political concerns about the sustainability of the revenue funding of two 'extra care' housing projects put forward by Housing and Health and Social Services Departments in May 2011 <sup>1</sup> , which have replaced Longue Rue House and Maison Maritainne residential care homes. |

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| <b>General Revenue</b>                 | Government income from taxes, charges and other sources. Under the structure of Guernsey's current tax system, this is heavily dependent upon income tax.   |
| <b>Grand Courtil, Le</b>               | Extra care housing developed by the Guernsey Housing Association, on the site of what was the Housing Department's Longue Rue House residential care home in St Martin's.   |
| <b>Guernsey Disability Alliance</b>    | The Guernsey Disability Alliance includes representatives from more than 30 local disability charities, as well as individual disabled people, their families, and the professionals who support them.  |
| <b>Guernsey Housing Association</b>    | A not-for-profit Housing Association providing social housing for rent and partial-ownership for local Guernsey people.   |
| <b>Handyperson Service</b>             | Offered by HSSD, this is a service for minor home repairs and adjustments (there is sometimes a charge for this service).   |
| <b>Health</b>                          | A state of complete physical, social and mental well-being and not merely the absence of disease or infirmity. Health is a resource for everyday life, not the object of living. It is a positive concept emphasising social and personal resources as well as physical capabilities. |
| <b>Health care</b>                     | Health care is care associated with treatment and management of long-term conditions via medication, therapy, diagnostics, treatment, and so on. This is in contrast to social care which focuses on supporting people to live their day-to-day lives.                                |
| <b>Health Information Guernsey</b>     | A third sector organisation providing information and advice to people about disability and health matters.   |
| <b>Health Visitor for Older People</b> | A community practitioner who helps senior members (over 65s) of the community to lead as healthy a life as possible, both physically and mentally, and to improve the quality of their lives by helping them to maintain their independence and keep safe and well in their own home. |
| <b>Home Helps</b>                      | HSSD's Home Help Service provides help with domestic jobs such as housework and ironing (there is sometimes a charge for this service).   |
| <b>Housing and Care 21</b>             | A national not-for-profit organisation providing housing and care for older people. In Guernsey housing and care 21 operate the extra care housing in Rosaire Avenue.   |
| <b>Housing Needs Survey</b>            | A survey undertaken every five years by the Housing Department to inform policy development in relation to current and future housing needs. See <a href="http://www.gov.gg/housingneedssurvey">http://www.gov.gg/housingneedssurvey</a>  |

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| <b>Housing with care</b>              | A term used to cover all housing where there is on-site care provision. This includes care homes, but also includes extra care housing and supported housing where a housing development has on-site care staff. The term was proposed by the 2014 UK Commission on Residential Care.  |
| <b>Hospice Care</b>                   | <p>Hospice care aims to improve the lives of people whose illness may not be curable. It helps people to live as actively as possible after diagnosis to the end of their lives, however long that may be. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. The highest value is put on respect and choice.</p> <p>Hospices not only take care of people's physical needs, they consider their emotional, spiritual and social needs too. And they support families and close friends, both during the illness and in bereavement.</p> |
| <b>'In Reach' Services</b>            | Services delivered by a health care or social care professional or team to a location within a community setting. An example would be specialist nurses coming into an extra care scheme to run a falls clinic, or continence advice, or a community nurse (see 'Community Nursing') coming into the scheme to promote flu vaccinations or other health programmes.  |
| <b>Independence</b>                   | The ability to carry out activities that support one's own lifestyle, and to have some control over how and where care and support is received.  |
| <b>Industrial Disablement Benefit</b> | This is a cash benefit payable to a person who has suffered a personal injury caused by an industrial accident, or suffers from a disease prescribed in relation to the person's employment, and has suffered a loss of physical or mental faculty. The amount of benefit payable is fixed by reference to the degree of disablement assessed by a medical board and expressed as a percentage.  |
| <b>Industrial Injury Benefit</b>      | This is a cash benefit available to a person who is unable to work through suffering a personal injury caused by an accident at work, or who suffers from a disease prescribed in relation to the person's employment.   |
| <b>Informal care</b>                  | Care provided by unpaid family members, friends and other informal helpers to individuals with care and support needs.   |
| <b>Integrated Care</b>                | Partnerships in which health care and social care staff share information appropriately and work together to ensure that people receive the support and care they need to remain independent in the community.   |
| <b>Integrated Services</b>            | Services taking a person-centred approach and seeking to meet a person's social and emotional needs as well as their physical and medical ones.  |
| <b>Intensive</b>                      | A community outreach service for people with long-term mental health   |

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| <b>outreach</b>                   | support needs.   |
| <b>Intermediate Care</b>          | Care provided to someone when they are at a stage of recovery where they still need health care and support at a level greater than would ordinarily be provided at home, but not at an intensive hospital level.  |
| <b>Invalidity Benefit</b>         | This benefit is payable to insured persons who for 26 weeks have been entitled to sickness or invalidity benefit and continue to be incapable of work, because of bodily or mental illness or disablement.   |
| <b>Island Development Plan</b>    | The Island Development Plan is a Development Plan, prepared by the Environment Department under section 8 of the Land Planning and Development (Guernsey) Law, 2005, which sets out the land planning policies for the whole of Guernsey in a single document.   |
| <b>Key Performance Indicators</b> | Quantitative measures on which data is gathered to monitor the success of a strategy, project or organisation at achieving a key objective.  |
| <b>Learning Difficulty</b>        | <p>Refers to specific learning problems. The umbrella term Specific Learning Disabilities (SpLD) is used to cover a wide variety of difficulties. Many people use it synonymously with dyslexia (a difficulty with words), but it is now generally accepted that dyslexia is only one of a group of difficulties that may include:</p> <ul style="list-style-type: none"> <li>• <b>Dysgraphia</b> – writing difficulty</li> <li>• <b>Dyspraxia</b> – motor difficulties</li> <li>• <b>Dyscalculia</b> – a difficulty performing mathematical calculations</li> <li>• <b>Attention Deficit Disorder, or Attention Deficit Hyperactive Disorder</b> (ADD or ADHD) – concentration difficulties with heightened activity levels and impulsiveness</li> <li>• <b>Asperger's Syndrome and Autism</b> – emotional behaviour or even social communication difficulties</li> </ul> |
| <b>Learning Disability</b>        | <p>Learning Disability is defined as referring to:</p> <ol style="list-style-type: none"> <li>A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;</li> <li>A significantly reduced ability to cope independently (impaired social and/or adaptive functioning);</li> <li>Which start before adulthood, with a lasting effect on development.</li> </ol> <p>This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An</p>  |

assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as people with Asperger’s Syndrome.

To clarify the definition further, it may be helpful to consider those people who would not be included in this definition:

- i. People who suffer brain injury in accidents after the age of 18
- ii. People with complex medical conditions which affect their intellectual abilities and which develop after the age of 18 – for example Huntingdon’s Chorea, Alzheimer’s Disease
- iii. People with some specific learning difficulties e.g. Dyslexia, Attention Deficit Hyperactivity Disorder.

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| <b>Lifeline Telephone system</b> | The Lifeline telephone system means help can be summoned in an emergency 24 hours a day by simply pressing a button on a telephone or on a pendant which is worn by the service user. This is arranged via Sure Ltd. to whom a line payment is paid for the service. (This is a form of <b>telecare</b> ).  |
| <b>Lifetime Homes standards</b>  | ‘Lifetime Homes’ are ordinary homes designed to incorporate design criteria from the outset that can be universally applied to new homes at minimal cost. In the Guernsey context this relates particularly to the need to incorporate design features in all new development, or to design development so that there is the potential to easily adapt it in the future, which can address the requirements of disabled residents or support the changing needs of occupants as they age (taken from the draft Island Development Plan, paragraph 19.9.15)        |
| <b>Lighthouse Wards</b>          | <p>The Lighthouse Wards (Hanois, Fougere and Casquets) are on the Princess Elizabeth Hospital site and provide specialist residential placements for people with complex physical needs. Their services are not age-specific but are need-led.</p> <p>One ward is specifically focused on complex behaviour associated with mental health conditions (especially dementia); one ward is for people with both complex behaviour and physical needs; and another is solely for complex physical needs. The current capacity is 53 with 2 short-break care beds.</p> |
| <b>Long-stay fee</b>             | This is a fee charged to people to contribute to their care costs when they are resident in the Lighthouse Wards, Duchess of Kent and Mignot Hospital Continuing Care Ward which is equivalent to the Long-term Care Co-payment.  |



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| <b>Long-term care</b>                  | It is the requirement for care and support by an individual that defines long-term care, <u>not</u> the place or situation where that care and support is provided. Long-term care thus encompasses a wide range of formal services, as well as the care provided by unpaid family members and other informal helpers. It is distinguishable from acute care as it is provided to individuals with enduring needs, including chronic, disabling conditions or impairments, who need support on a permanent or ongoing intermittent basis.   |
| <b>Long Term Conditions</b>            | Illnesses which last longer than a year, usually degenerative, causing limitations to one's physical, mental and/or social well-being. Long Term Conditions include Diabetes, Chronic Obstructive Pulmonary Disease, Asthma, Arthritis, MS, Parkinson's Disease, Epilepsy, and Mental Health. Multiple Long Term Conditions make care particularly complex, and a small number of individuals and conditions require complex care packages and high levels of health care use (especially hospital care). According to the World Health Organisation, Long Term Conditions will be the leading cause of disability by 2020. |
| <b>Long-term Care Benefit</b>          | Long-term Care Benefit is a weekly benefit which is paid towards the cost of the fees if you are in a private residential home or private nursing home. (NB. "Private" means not run by the States.)  |
| <b>Long-term Care Insurance Fund</b>   | Money raised via Social Security Contributions for the purpose of Long-term Care is kept in a Fund which is managed as an investment. This is called the Long-term Care Insurance Fund.   |
| <b>Long-term Care Insurance Scheme</b> | The Long-term Care Insurance Scheme describes the system under which Long-term Care Benefit operates including the benefit payments and fund as prescribed by the Long-term Care Insurance (Guernsey) Law, 2002.  |
| <b>Long-term Hospital Care</b>         | Where an individual has acute or complex needs which necessitate a long-term stay in a hospital setting.  |
| <b>Longue-Rue House</b>                | The Residential Care Home which was operated by the Housing Department in St Martins, which has now been redeveloped into Le Grand Courtil extra care housing.  |
| <b>Maison Maraitaine</b>               | The Residential Care Home which was operated by the Housing Department in the Vale, which has now been redeveloped into La Nouvelle Maraitaine extra care housing.  |
| <b>Managed Personal Budget</b>         | Where a social worker works with the person with care needs to identify what services they want to spend their personal budget on from a 'menu' of approved providers, and then arranges for these services to be paid for from the personal budget without the individual needing to contact care  |



agencies themselves or handle the money.

**Meals on Wheels** Deliveries of pre-cooked meals to the homes of people who are housebound and/or are unable to prepare meals and/or cook for themselves. (NB. This could also be the delivery of frozen meals for the individual to prepare themselves, although this service is not available in Guernsey.)

**Medical Specialist Group** Provides the emergency and elective specialist medical services for the Bailiwick of Guernsey, Alderney and Herm within the secondary health care framework and in partnership with the Health and Social Services department.

**Medical Model of Disability** “The social model of disability says that disability is caused by the way society is organised. The medical model of disability says people are disabled by their impairments or differences.

Under the medical model, these impairments or differences should be 'fixed' or changed by medical and other treatments, even when the impairment or difference does not cause pain or illness.

The medical model looks at what is 'wrong' with the person, not what the person needs. It creates low expectations and leads to people losing independence, choice and control in their own lives.”

<http://www.scope.org.uk/about-us/our-brand/social-model-of-disability>

**Memory Clinic** A clinic to which individuals with memory problems are referred in order to assist with diagnosis.

**Mental Health** “Mental Health affects us all. How we think and feel about ourselves and our lives impacts on our behaviour and how we cope in tough times.

It affects our ability to make the most of the opportunities that come our way and play a full part amongst our family, workplace, community and friends. It's also closely linked with our physical health.

Being mentally healthy doesn't just mean that you don't have a mental health problem.

If you're in good mental health, you can:

- Make the most of your potential
- Cope with life
- Play a full part in your family, workplace, community and among friends

We all have times when we feel down or stressed or frightened. Most of the time those feelings pass. But sometimes they develop into a more serious problem and that could happen to any one of us. Your mental health doesn't always stay the same. It can change as circumstances change and as you move through different stages of your life.

There's a stigma attached to mental health problems. This means that people feel uncomfortable about them and don't talk about them much. Many people don't even feel comfortable talking about their feelings. But it's healthy to know and say how you're feeling."

Mental Health Foundation: <http://www.mentalhealth.org.uk/help-information/an-introduction-to-mental-health/what-is-mental-health/>

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| <b>Mental Health and Wellbeing Strategy</b> | In February 2013, the States of Deliberation approved a report from the Health and Social Services Department outlining a Mental Health and Wellbeing Strategy <sup>115</sup> . The Strategy is intended to promote mental health and wellbeing across the community, support vulnerable people, and ensure that appropriate and effective treatment is provided for those who need it. |
| <b>Metivier House</b>                       | A Guernsey Housing Association development of 14 flats of sheltered housing which is supported by staff from Le Grand Courtil extra care site.  |
| <b>Mignot Memorial Hospital</b>             | The hospital in Alderney, which includes a Continuing Care ward for individuals in Alderney with long-term nursing care needs.  |
| <b>Multi-Disciplinary Assessment</b>        | Assessment of an individual's needs that actively involves professionals from different disciplines in collecting and evaluating assessment information.  |
| <b>Needs</b>                                | What an individual requires to achieve and maintain health and well-being. Areas of needs include: physical, emotional, mental health, spiritual, environmental, social, sexual, financial and cultural.  |
| <b>Needs Assessment</b>                     | A process by which health care and social care professionals assess and then make conclusions on risks and needs. The assessment sets out what is necessary for an individual to maintain their life at a certain standard.   |
| <b>Needs Assessment Panel</b>               | The Needs Assessment Panel is a body of professionals convened by HSSD to make decisions on where an individual's needs will be most appropriately met. A certificate confirming the level of need is required from the panel to access most forms of bed-based care.   |

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<sup>115</sup> Health and Social Services Department – 'Mental Health and Wellbeing Strategy' – Billet d'État III 2013.

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| <b>Night Sitting Service</b>             | A carer provides personal care and support services to an individual in their own home over night.  |
| <b>Not-for-profit</b>                    | An organisation or company which may charge for services but reinvests any surplus revenue to further its purpose rather than distributing profits to shareholders or owners.   |
| <b>Nursing Care</b>                      | Involves the use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health; to cope with health problems; and to achieve the best possible quality of life, whatever their disease or disability, until death. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people.   |
| <b>Nursing Home</b>                      | Care home that provides nursing care (with, generally, at least one registered nurse on duty).  |
| <b>Occupational Therapy</b>              | Occupational therapists work with people who have a physical impairment, a medical condition, a mental condition problem or a learning disability. They help people who have difficulties with practical everyday tasks. The aim of occupational therapy is to enable individuals to live as independently as possible – at home, in employment, or in education. Occupational therapists work in health and social care and work closely with health, housing, and educational services. An occupational therapist can help individuals adapt to changes in everyday life caused by disability or illness and to overcome practical problems. Occupational therapists have specialist knowledge and can advise on equipment, housing adaptations, and adaptations to the workplace (see ‘Aids and Adaptations’). |
| <b>Off-Island Placements</b>             | Where an individual presents with high-level or specialist needs which cannot be effectively met on-Island, long-term placements are arranged to enable an individual to be appropriately supported elsewhere, mostly in the UK.  |
| <b>Older Adult Mental Health Service</b> | A service which supports the mental health needs of people over retirement age, incorporating but not limited to dementia. The service operates a community team, an assessment ward, the Duchess of Kent and Lighthouse Wards.   |
| <b>Older People’s Strategy</b>           | A strategy which was under development until 2011 which was not presented to the States, but developed into the Supported Living and Ageing Well Strategy.  |
| <b>‘Outreach’ Services</b>               | Describes those services or facilities which are managed within a specific location (for instance an extra care scheme) and delivered from that location into community settings. Outreach Services might also be a specialist care or support service. An example of this kind of Outreach   |

Service might be an Assistive Technology response service, where staff based at an extra-care scheme respond to community alarms triggered by people who live in the surrounding community.

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| <b>Palliative Care</b>        | Palliative care is the term used to describe the care that is given when cure is not possible. The word comes from the Latin 'palliatus' (covered or hidden with a cloak) and is used to mean 'relieving without curing'. Palliative care is a proactive approach involving a multi-professional team. As well as controlling pain and other distressing symptoms, it applies a holistic approach to meeting the physical, practical, functional, social, emotional, and spiritual needs of patients and carers facing progressive illness and bereavement. Although historically associated with the later stages of cancer, it is now established that palliative care should also be a routine part of end of life care for those living with and dying from a wide variety of non-malignant conditions, such as Dementia, Heart Failure, Huntington's Disease, Motor Neurone Disease, MS, Muscular Dystrophy, Parkinson's Disease, Renal Failure, and Respiratory Failure among others. |
| <b>Palliative Care team</b>   | A multi-disciplinary community team providing palliative care support.  |
| <b>Person Centred Care</b>    | Person centred approaches are ways of commissioning, providing, and organising services rooted in listening to what people want, to help them live in their communities as they choose. These approaches work to use resources flexibly, designed around what is important to an individual from their own perspective, and work to remove any cultural and organisational barriers. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person. Health care and social care agencies are increasingly using 'individual' or 'person' or 'citizen' as a term in place of traditional, organisational specific terms such as customer, client, service user, and (where appropriate) patient. (NB. HSSD has adopted the term 'service user'.)  |
| <b>Personal budgets</b>       | A way of funding long-term care currently used within the UK. A personal budget is an amount of money set aside to purchase a person's care and support from third-party organisations based on an assessment of their needs.   |
| <b>Personal contributions</b> | In this report, used to describe any case in which an individual is asked to contribute financially towards the cost of their care.   |
| <b>Personal Care</b>          | Providing assistance with dressing, feeding, washing and toileting, taking medication, as well as advice, encouragement, and emotional and psychological support.   |
| <b>Personal expenses</b>      | Items for which individuals might have to pay when they are living in a   |

residential long-term care setting, for example a ward or care home. This might include hairdressing, gifts, chiropody, incontinence pads, toiletries etc.

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| <b>Personal Tax Pensions and Benefits Review</b> | A comprehensive review of personal taxes, allowances and benefits undertaken by the Treasury and Resources and Social Security Departments and debated by the States in March 2015.   |
| <b>Physiotherapy</b>                             | Physiotherapy is a science-based healthcare profession which views movement as central to health and well-being. Physiotherapists aim to identify and make the most of movement ability by health promotion, preventative advice, treatment and rehabilitation. Physiotherapists believe it is of vital importance to take note of psychological, cultural and social factors which influence their clients. They try to bring patients into an active role to help make the best use of independence and function. |
| <b>Positive Behaviour Support Team</b>           | A team based in the Learning Disability Service which helps service users and staff to manage and reduce challenging behaviour.   |
| <b>Preventative Services</b>                     | These services are associated with preventing the onset of situations or conditions that could lead to acute service responses. Services are associated with the promotion of health and the prevention of disease. An example of a preventative health programme would be 'Walk Your Way to Health', a programme offered by the Guernsey Health Promotion Unit.  |
| <b>Primary Care</b>                              | Health services offered by providers who act as the principal point of consultation for patients within a health care system, e.g. doctors, dentists, pharmacists. These are services which someone can access directly without referral.   |
| <b>Private Nursing and Domiciliary Care</b>      | Nursing care and other support services provided by voluntary, charitable and not for profit organisations and private businesses (i.e. not by the States).   |
| <b>Provider</b>                                  | Organisations or care staff that supply services.   |
| <b>Public Engagement Steering Group</b>          | A group composed of representatives of Ageing Well in the Bailiwick, the Guernsey Disability Alliance and the States' Champion for Disabled People who supported the Working Party in the development of the Strategy.  |
| <b>Public Health</b>                             | The prevention of disease and promotion of health through the development of evidence-based programmes. A directorate of HSSD incorporating health promotion.   |
| <b>Rapid response</b>                            | A team which provides short-term rapid access to additional support in  |

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| <b>team</b>                  | crisis situations for people or their carers to manage an escalation of need and prevent hospitalisation if possible.  |
| <b>Re-ablement</b>           | The active process of regaining skills, confidence, and independence.  |
| <b>Rehabilitation</b>        | A multidisciplinary process which supports the individual to achieve their maximum potential to function physically, socially, and psychosocially through support and intervention.  |
| <b>Residential Home</b>      | Care home that does not provide nursing care, but provides support with activities of daily living in a group home setting with shared communal facilities.  |
| <b>Respite Care</b>          | Short-term care for a person to allow their carer a break from caring. This can be in the form of in a care environment (i.e. in a respite home), short breaks, outreach support, or day care.   |
| <b>Risk, Risk Assessment</b> | <p>When a holistic assessment is completed, the assessor and the individual consider and evaluate conclusions on the risks and needs. This evaluation also takes full account of the likely outcome if assistance were not to be provided. There are also specialised risk assessments for specific types of risks, i.e. violence and aggression, manual handling.</p> <p>The evaluation of risk focuses on the following aspects that are central to an individual's independence: autonomy and freedom to make choices; health and safety including freedom from harm, abuse and neglect, taking uses of housing circumstances and community safety into account; the ability to manage personal and other daily routines; and the involvement in family and wider community life, including leisure, hobbies, unpaid and paid work, learning and volunteering.</p> <p>Assessors also consider risks faced, not only by the person assessed, but by those close to them, such as carers (and to staff and society). They also consider which risks cause serious concern and which may be acceptable or can be viewed as a natural healthy part of independent living.</p> |
| <b>Sarnia Ward</b>           | A ward used for the assessment of older adults presenting with mental health needs.  |
| <b>Secondary Care</b>        | Hospital Care resulting from a referral by a health professional in Primary Care.  |
| <b>Senior Carer Service</b>  | Home care workers who give help with personal care such as washing and dressing, going to the toilet, and provision of simple meals.   |
| <b>Service charge</b>        | The amount an individual is charged in extra care housing, or other rental accommodation over and above rent for services provided (e.g. cleaning  |

of communal areas).

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| <b>Service Level Agreement (SLA)</b> | Service level agreements are agreements between the States and organisations that provide services stating what it is expected that the organisation will provide in exchange for funding.   |
| <b>Severe Disability Benefit</b>     | Severe Disability Benefit is a weekly benefit intended for adults and children who have a physical or mental impairment and need a lot of attention or supervision by day or night. It can be used for a range of purposes including equipment purchase, additional heating, transport, therapy, care and support and more.  |
| <b>Sheltered Housing</b>             | Independent housing units (flats, bungalows, houses) that are linked to a community alarm service and with a warden who can help people access support services which enable them to live independently for as long as possible. Generally associated with older people.   |
| <b>Shopping service</b>              | A service provided by HSSD to assist people with shopping where necessary. There is a minimal charge for this service.   |
| <b>Short-break service</b>           | Services which both enable those individuals with care or support needs to spend time with people, be in places or undertake activities that would not otherwise be available to them, and can also enable those who care for others to have a break from caring.  |
| <b>Single Assessment Process</b>     | Standardised holistic assessment framework across health care and social care so duplication is minimised and an individual receives timely and proportionate assistance appropriate to their risks and needs. The Single Assessment Process aims to put individuals at the centre of their own assessment and subsequent personalised care planning. Originally brought in for older people, it is increasingly being used as the framework for other adult groups.   |
| <b>Sitting service</b>               | This service can help carers to have a break from looking after someone at home; day care may be provided for people who live in the community.  |
| <b>SLAWS Working Party</b>           | A Working Party formed to progress the Strategy formed of representatives of the Treasury and Resources, Social Security, Health and Social Services and Housing Departments.  |
| <b>Social Care</b>                   | “The provision of social work, personal care (but not nursing or medical care), protection or social support services to children in need or at risk and their families and carers, or adults at risk or with needs arising from illness, disability, old age or poverty and their families or other carers. That provision may have one or more of the following aims: to protect service users, to preserve or advance physical or mental health, to promote independence and social inclusion, to improve opportunities |

and life chances, to strengthen families and protect human rights in relation to people's social needs''' *Social Care Institute for Excellence*

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| <b>Social housing</b>                | Housing provided by the States or third-sector not-for-profit providers to individuals with unmet housing needs. This can include affordable housing, related to the financial ability of individuals to cover their housing costs, but also to specialised housing – such as extra care housing, which caters to specific needs and access to which is not income-based.   |
| <b>Social model of disability</b>    | <i>“The social model of disability identifies systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) that mean society is the main contributory factor in disabling people i.e. it is the society as a whole that is responsible for creating barriers to full participation of persons with disabilities, and it is the society as a whole that has the responsibility to remove them.” (Delia Ferri, 2011)</i>   |
| <b>Social Policy Group</b>           | A sub-group of the Policy Council comprising the Chief Minister and Ministers of the Home, Health and Social Services, Education, Social Security, and Treasury and Resources Departments.  |
| <b>Social Policy Plan</b>            | Part of the <b>States Strategic Plan</b> . The purpose of the Social Policy Plan is to assist the States to develop and deliver services for people to meet their needs for welfare and wellbeing. The areas covered by the Plan include health; social care; benefits; housing; employment; equality; education and security..   |
| <b>Social Security Contributions</b> | The amount individuals and employers pay from their income towards Social Security. This funds contributory benefits including pensions and long-term care benefit. Currently only individuals, and not employers, contribute to the Long-term Care Fund.   |
| <b>Social Services</b>               | <p>Personal social services is one of the major public services and describe a wide range of support that help people to carry on in their daily lives. It includes:</p> <ul style="list-style-type: none"> <li>• Services for children such as adoption, fostering and protection;</li> <li>• Help for people with mental health needs;</li> <li>• Support and care services for older people;</li> <li>• Support for people with a disability and people with learning disabilities.</li> </ul> <p>The term social care is increasingly now being used instead of social services. This reflects the greater involvement of the independent sector and voluntary sector in the provision of social care services and the continuing role of the ‘statutory’ sector as commissioners as well as providers of support and care. Social services functions in many</p> |



jurisdictions no longer stand alone, but are increasingly combined with housing, education, and health services.

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| <b>Social Worker</b>                        | Professionals who are available to provide information about services in Guernsey and to discuss with people which service may be appropriate for their needs, particularly regarding carer support and help to stay living at home. They call upon a range of expertise to assist with complex problems. They also undertake comprehensive assessments for people who require residential home or nursing home care. |
| <b>Specialised Housing</b>                  | A land-planning use-class which incorporates care homes and supported housing – any housing where there is on-site care provision.  |
| <b>Specialist Residential Care home</b>     | Care home that does not provide nursing care, but provides support with a range of activities of daily living in a group home setting with shared communal facilities providing for individuals with specialist needs e.g. dementia.  |
| <b>States' Champion for Disabled People</b> | A Deputy elected by disabled islanders and carers to act as their champion in the States.   |
| <b>States Strategic Plan</b>                | The States Strategic Plan (SSP) is the long-term planning mechanism to enable the States to decide what they want to achieve over the medium- to long-term and how they will manage or influence the use of Island resources to pursue those objectives. The latest version of the States Strategic Plan was considered and approved by the States in March 2013.   |
| <b>“States rates”</b>                       | An informal term used to refer to care home placements which are the sum of Long-term Care Benefit and the Co-payment and for which no additional top-up fee paid by the individual is required.  |
| <b>States Review Committee</b>              | A committee formed by the States to make recommendations on the reform of the machinery of Government. Changes, including the restructuring of departments into new committees, will take place during 2016.  |
| <b>St John Ambulance Subscriptions</b>      | An annual subscription scheme to meet the cost of emergency ambulance services.   |
| <b>St Julian's House</b>                    | Managed by HSSD to accommodate and support on a temporary basis vulnerable men and women (max. 32) who would otherwise be homeless, in mostly dormitory-style accommodation.  |
| <b>Strategic Land Use Plan (SLUP)</b>       | One of four Island Resource Plans which describe the ways in which the States proposes to manage or influence the use of Island Resources to support the overall Aims and Objectives of the States Strategic Plan. The  |

SLUP sets out a 20-year agenda for land use planning in Guernsey and has been used by the Environment Department to guide the preparation of the draft Island Development Plan.

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| <b>Supplementary Benefit</b>                    | Supplementary Benefit is a cash benefit intended to bring household income up to a level which the States believes is enough to live on. The amount of benefit receivable is calculated on a weekly basis with reference to household income.   |
| <b>Support Services</b>                         | Support services include services which enable independent living, such as help to arrange shopping; housekeeping; helping to complete benefit claims; providing links to other community or voluntary services like Age Concern, GVS, etc.; providing links to States' services where necessary; arranging social events; help with laundry, meal preparation, etc.  |
| <b>Support Time and Recovery (STAR) Service</b> | A community based mental health service to assist individuals recover from medium to long-term mental health conditions.  |
| <b>Supported Housing</b>                        | Independent housing units (flats, bungalows, houses) that are designed to help people with a range of needs to live independently for as long as possible. Generally associated with adults under pensionable age.  |
| <b>Tax burden</b>                               | The proportion of a person's income that they are paying in tax and social security contributions.  |
| <b>Telecare</b>                                 | A combination of equipment, monitoring and response that can help individuals to care for themselves or call for help. It can include basic community alarm services able to respond in an emergency and provide regular contact by telephone, as well as detectors which detect factors such as falls, fire or gas and trigger a warning to a response centre. Telecare can work in a preventative or monitoring mode, for example, through monitoring signs, which can provide early warning of deterioration, prompting a response from family or professionals. Telecare can also provide safety and security by protecting against bogus callers and burglary. |
| <b>Telehealth</b>                               | Telehealth is technology which can support the provision of healthcare remotely. For example, it can allow a medical specialist to have a video conference meeting with someone in a remote location, or carry out certain tests from a distance.   |
| <b>Third Sector</b>                             | Term used to describe the range of groups and organisations including small local community and voluntary groups, registered charities both large and small, foundations, trusts, and the growing number of social enterprises and co-operatives. Third sector organisations share common characteristics in the social, environmental, or cultural objectives they pursue; their independence from government; and in the reinvestment of  |

surpluses for those same objectives. So, as well as including charities and support groups, the third sector also includes not-for-profit housing and care providers.

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| <b>Third sector compact</b>    | An agreement between the States of Guernsey and the Association of Guernsey Charities made in 2014 outlining the ways in which the public and third sectors would work together.  |
| <b>Top-up fee</b>              | The amount which a care home might charge over and above the sum of the Long-term Care Benefit and Co-payment. This cost is usually met by the individual from their personal resources. See section 7.2.1 for further.   |
| <b>Transition</b>              | Generally refers to the transition from children and young people's to adult services which occurs in late teens or early twenties.   |
| <b>Travel Allowance Grants</b> | A grant given by the Social Security Department to those travelling off-Island for medical assessment and/or treatment to cover the costs of their travel   |
| <b>Unit cost</b>               | The amount it costs per unit of a service delivered, e.g. the cost to provide a bed in a care home per night or an appointment with community services staff.   |
| <b>Unmet Need</b>              | Social care needs that are not met because of lack of awareness, because there are not enough resources or because the services are not of a sufficiently high standard.  |
| <b>User Involvement</b>        | Involving individuals in the planning and development of the services they use. There is a need for a range of models of involvement, depending on the level of activity that participants wish to commit. What is important is that the choice is there, and that the involvement – or partnership – is real. User involvement should relate clearly to a decision that the organisation plans to make, and is open to influence. It should be made clear what individuals may or may not be able to change. |
| <b>Voluntary Car Service</b>   | Helps those who need it with transportation to medical appointments (e.g. an older person living in the community who has an appointment with a General Practitioner or with the Medical Specialist Group). This service is provided by volunteer personnel. It is not accessible to people with physical or sensory impairments who require assistance.  |
| <b>Vulnerable Person</b>       | An individual who is at risk of abuse or harm due to life circumstances, for example, a homeless person or a frail older person, or personal choice, e.g. an individual may decide to continue with the risk.   |
| <b>Well-being</b>              | The state of being healthy, happy, and prospering. An individual's health and well-being is affected by a number of different factors that  |

contribute positively to health and well-being such as:

- A balanced diet;
- Regular exercise;
- Supportive relationships;
- Adequate financial resources;
- Stimulating work, education, and leisure activity;
- Use of health monitoring and illness prevention services (such as screening and vaccination);
- Use of risk management to protect individuals and promote personal safety.

**Working Party**

See **SLAWS Working Party** or **Funding of Long-term Care Working Party**

## Appendix B - SLAWS Working Party Terms of Reference

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The Working Party is commissioned by the Social Policy Group.

### Objectives

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The Working Party will meet until the following objectives are fulfilled:

- The production of a draft States Report outlining:
  - The establishment of a set of policy principles
  - The primary aim will be the development of these principles into a coherent strategy answering the following three key points:
    - what care, support and accommodation services will be provided,
    - by whom
    - and how they will be paid for.
  - Provision of a sound evidence base for the Strategy.
  - Demonstration that the proposed provision can be funded sustainably.
  - Recommended programme of actions to bring service provision in line with the underlying principles, including the cost, method of implementation and priority of the changes proposed.
- This report produced with reasonable consideration of the views of internal and external interested parties, especially the Health and Social Services, Housing, Social Security and Treasury and Resources boards, existing care and support service providers and supported accommodation providers, older people, and disabled adults.
- The Report will be a Policy Council Report and will be submitted to the States before the end of the political term.

### Composition

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The group will be composed of the Chief Minister and nominated Deputies representing the Housing, Social Security, Health and Social Services, and Treasury and Resources Boards. It will be supported by the SLAWS Project Executive and Project Manager, and a nominated staff representative of each of the four departments (Housing, Health and Social Services, Social Security and Treasury and Resources).

### Chair

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The Chief Minister will Chair the Working Party.

### Escalation

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Should a risk arise which jeopardises the achievement of the above objectives, the Working Party should raise this to the attention of the Social Policy Group at the earliest opportunity.

## Appendix C – Principles and Objectives

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The following high level principles were agreed by the Working Party and later modified into the priority outcomes included in section 1.4 above in light of feedback from the consultation.

**The SLAWS aims to:**

- 1) Promote, improve and protect individuals' health, wellbeing and dignity;
- 2) Ensure there are opportunities for independence and choice;
- 3) Enable fair access to appropriate care and support, and suitable housing;
- 4) To establish a partnership culture whereby the public, private and third sectors, service users and their carers can each contribute to service delivery and development and share information appropriately;
- 5) To have regard to affordability and financial viability for the funders, providers and recipients of care and support services;
- 6) To ensure that service provision and funding options are sustainable in the medium to long term; and
- 7) To ensure safe, quality care and ensure standards through appropriate regulation.

**By pursuing these, the Working Party considered that the following outcomes should be progressively realised:**

- (a) Reduction, where possible, of the incidence of adults (aged 18+) having enduring care, support or supported accommodation needs by, where possible, preventing needs from arising or increasing;
- (b) Improved outcomes for all adults (aged 18+) with enduring care, support or supported accommodation needs (see below); and
- (c) Protection of the health and well-being of the carers of those with care and support needs.

## Appendix D - Consultation Summary of Findings

 STATES OF GUERNSEY

# **THE SUPPORTED LIVING AND AGEING WELL STRATEGY (SLAWS) CONSULTATION**

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## **SUMMARY OF FINDINGS**



## FOREWORD

**The Supported Living and Ageing Well Strategy will lay the ground work for the development of a more sustainable, person-centred system of care and support for those Islanders with ongoing care and support needs.**

The input of Islanders, States' departments and community groups has been a key part of this development process. However, the completion of this consultation is only the first stage of what will be an ongoing process of engagement and development as we take forward the Strategy over the years to come. Whilst work to date and the recent consultation have focused on the broad strategic picture, there will, undoubtedly, be further engagement and consultation to refine the details.

We are pleased to have received so many responses and are now taking these into consideration as we prepare to take an initial Policy Letter to the States for debate in early 2016. This Policy Letter will set the direction of travel for what will certainly be a long and demanding journey, but one which we have to undertake for the benefit of the entire community, not just those Islanders that will need care and support services.

There will be no easy solution to managing increasing demand for services or addressing the gaps and issues identified. However, we believe that by working together we can build on the good services we have, recognise the areas that require development and work in partnership with all of the people and organisations that provide care and support across the Islands to ensure that we have a deliverable plan for our future.

**Deputy Peter Harwood**

Chair of the Supported Living and Ageing Well Strategy Working Party

**Working Party members:**

- > Deputy Hunter Adam (Treasury and Resources Department)
- > Deputy Sandra James (Social Security Department)
- > Deputy Michelle Le Clerc (Health and Social Services Department)
- > Deputy Paul Le Pelley (Housing Department)



The following summary of responses is intended to reflect the content of responses to the consultation from members of the public and organisations. It does not represent the views or decisions of the Supported Living and Ageing Well Working Party.

It is recognised that the consultation respondents were a self-selecting sample and this consultation is by no means a representative survey, nor was it intended to be. Nevertheless, it offers valuable insights into the concerns in our communities about the key areas under consideration.

## PART ONE – SUMMARY

The Supported Living and Ageing Well Strategy aims to review the care and support services and funding available for all adult (18+) Islanders with enduring care and support needs. This includes support for people who live in their own homes and are cared for by family and friends, those who use community services and day centres, people living in supported or extra-care housing, people living in residential or nursing care homes, people in long-stay hospital wards and people in long-term off-Island placements.

It also includes, but is not limited to, people with learning disabilities, autism, brain injury, physical impairments, chronic illness, sensory impairments, mental health conditions, neurological conditions, dementia, and conditions associated with ageing.

The Strategy will aim to provide a strategic overview and direction to enable services to develop in a more person-centred, co-ordinated and sustainable way. Whilst an initial Policy Letter is being prepared for States Debate in early 2016, this will only be a first stage and the Strategy will continue to be developed and to shape long-term change over the coming decades.

In order to inform the development of the initial report, a consultation was prepared and was open to the public from 22<sup>nd</sup> June to 22<sup>nd</sup> July 2015. The consultation release was publicised in local media and it was possible to respond online or via paper forms/documents. Three public meetings were held, one of which was in Alderney. The consultation covered the underlying strategic principles; the role of the public sector in care provision; the structure of service delivery; social attitudes towards care, disability and ageing; and the funding of care and support services.

## RESPONSES TO THE CONSULTATION

In total 309 responses were received to the consultation. These have been considered alongside a number of letters and emails which were received and comments made in public meetings. This summary report draws together findings from all of these sources. Typically, respondents did not answer all of the questions. Demographic information about respondents, where available, is included in Part Two below (Q59-61).

Whilst compliments were received from some on the consultation documents, some members of the public reported finding the consultation hard to find, too lengthy, wordy or complex. Some expressed a desire for the consultation to have been more

widely publicised, more actively taken out to relevant constituents and illustrated with case studies to show what it meant for people in real terms. A few highlighted that the timescale was rushed and coincided with other key public consultations. Better use of focus groups in future consultations was suggested. A few respondents were concerned that the consultation documents and exercise was overly expensive and ‘wasteful’. A few felt that the wording of questions was leading or poorly thought through.

Alderney residents were concerned that some of the questions were not relevant to them.

There was a technical issue with three of the questions which involved ranking options (18, 21 and 34). This seems not to have worked on all computer systems, and some respondents felt that they could not rank the options in any case (i.e. that all options were equally important). The discussion in Part Two endeavours to take account of these issues.

## KEY EMERGING THEMES

Whilst responses are considered question by question in Part Two, the following summarises the key themes that emerged from the analysis of responses.

**Support for the principles and strategic direction** (*Part 2, Section B of consultation document, pg 30-33, available at: [www.gov.gg/slaws](http://www.gov.gg/slaws)*)

The vast majority of respondents supported the principles (see **Box A**, page 11 below) and strategic direction. There was some concern that the principles were vague and that key concepts, such as ‘fairness’, were open to interpretation. There was also some scepticism about the ability of the States to implement a strategy which would achieve these principles.

**Role of the public sector** (*Part 2, Section C of consultation document, pg 34-41*)

There was both wide support for the role of the States as the “strategic planner” (see **Box B**, pg 17 below) and also a general sense that this was not being done well at the moment. Poor coordination of existing services, lack of information and advice about services, and lack of regulation and safeguarding were key themes.

The importance of partnership working was also widely recognised, although there were some concerns raised about the capacity of the third sector in its current form and the potential/perceived risk of over-reliance on the third sector for key service provision. A question was also raised over whether the States had the skill-set to engage properly with community organisations. Several organisations expressed a strong interest in working with the States to address some of the issues identified in the SLAWS consultation.

Questions were raised about how the States of Alderney fitted into the 'strategic planner' picture.

In terms of who should provide care and support there was a range of opinions with some strongly held views about whether the public sector should or should not provide care and support services. Others felt that it was not important who provided services as long as they were provided well. There was more support for increasing provision in the public and third sector than in the private sector, or increasing the amount of care provided within families.

**A different way of delivering services** (*Part Two, Section D of consultation document, pg 42-55*)

**Person-centred** - there was support for making services more person-centred and some dissatisfaction with the degree to which existing services achieved this.

**Coordinated** - most of the people who had been in contact with multiple services felt that coordination of services needed to be improved. The idea of a single point of coordination was popular amongst those who commented.

**Balance between institutional care and home care** - whilst there were a number of respondents who expressed the desire to stay in their own home until the end of their lives, others were keen that care homes remained an option as the best way to meet some people's needs. There were mixed opinions on extra-care housing.

There was significant indication that people were having difficulty finding out about and accessing the community services that they needed.

**Role of GPs** - Whilst the role of GPs and their inclusion in discussion over developments was recognised as key there was little support for the idea of GPs as key coordinators of care and support services for individuals – the role was recognised as necessary but that GPs may not be best placed to undertake it.

**The range of services and support** (*Part Two, Section E of consultation document, pg 56-66*)

**Mental Health** – there was significant concern about mental health provision. A particular issue was gaining access to it when needed both in terms of waiting times and out-of-hours services.

**Dementia** – there was support for the identification of dementia services as an area in need of development.

**Support to carers** – this was recognised as important and a service gap within the current system, with a lack of support and advice for those who cared for family and friends.

**Respite care** – there was strong support for the view that respite care is currently under-developed. Responses suggested that there was a lack of awareness of services which were available, that what was offered was not always appropriate, and that lack of availability led to people turning to the private sector for support which was often costly.

**Gaps in housing with care** – as suggested by the data in Part Two, there was strong support for developing a greater range of housing with care options (i.e. residential, nursing and specialist care homes, supported and extra-care housing where there are on-site care staff).

**Changing the way we think about care, disability and ageing** (*Part Two, Section D of consultation document, pg 68-70*)

Responses emphasised the importance of social inclusion and services which enabled people and supported the mental wellbeing of people with care and support needs and their carers. Addressing discrimination, loneliness and supporting people to live meaningful lives and pursue interests were also highlighted as important to respondents.

Some respondents felt that the discussion of the ageing demographic in the media was overly negative. Others were concerned that existing care services for younger disabled people did not support them to “have a life” and to have equal opportunities to participate in society.

**How do we pay for care and support?** (*Part Two, Section D of consultation document, pg 71-95*)

Many of the funding issues saw significant differences of opinion between respondents, with some inconclusive results.

Whilst there were a few reservations, most respondents supported the pursuit of prevention, re-enablement, independent living and innovation to avoid costs increasing as rapidly as they otherwise would.

A significant number of comments favoured a modest increase in Social Security contributions over making increased personal payments when need arose.

Whilst there was a range of opinions, most respondents did not support the inclusion of property assets in means-testing when someone needed care or support.

**Other key themes**

Throughout the consultation the following themes emerged:

**Information and advice** – throughout the consultation respondents commented that, or related experiences which suggested that, they had significant difficulty finding out about what services were available. This is a theme which was identified in the Disability and Inclusion Strategy (2013), and one which that Strategy is currently seeking to address.

**Care and support staffing** – difficulty obtaining and retaining staff, continuity of carers, and training of care professionals was a significant concern to some respondents.

**Quality of life** – several key stakeholders highlighted the importance of working towards the wider quality of life of older adults and adults with care and support needs.

**Importance of prevention and re-enablement** – some respondents felt that the focus on prevention and re-enablement should be stronger.

**Transition** – some respondents felt that further attention should be given to the transition of young adults from children and young people's services into adult services and/or independent living.

***Building care around personal relationships*** – the importance of having care and support options which took into account an individual’s personal context and relationships was highlighted.

***Lifelong learning and employment of older people*** – some felt that lifelong learning and the employment of older people should be considered as part of the Strategy. This had been consciously excluded from consideration in order to prioritise focus on care and support for all adults at this stage of the Strategy’s development.

It is important to note that as part of the Personal Taxation, Pensions and Benefits Review, the States agreed: “To direct the Social Security Department, in consultation with all other relevant departments, to investigate measures aimed at supporting longer working lives and assisting older people who wish to work to remain in the workforce, and to report to the States of Deliberation with its findings no later than December 2017.” (Billet IV, March 2015)

***Equipment and adaptations*** – some respondents raised concerns about the current equipment and wheelchair provision.

## ALDERNEY

Alderney respondents highlighted the need for the island to be incorporated into the whole Strategy rather than to see Alderney as an ‘add-on’. However, there were also some issues raised which were specific to Alderney that may need special consideration.

Although the sample size for the responses from Alderney was small (with only 12 respondents identifiable as living on, or operating in, Alderney), some differences emerged. N.B. It is not clear whether these are due primarily to the sample size or if they are due to differences in views between the islands’ populations.

Alderney respondents:

- showed weaker support for the underlying principles
- showed less support for working in partnership with the third and private sector
- showed stronger support for increased public sector provision (as opposed to private, or not-for-profit)
- tended to rate experience of services lower

- reported less difficulty with social attitudes about ageing
- felt that care staff were more likely to enable the person they cared for rather than do things for them, compared with respondents as a whole
- were marginally more supportive than respondents as a whole of incorporating the value of property in means-testing

A number of further comments were received, these included:

- that it would be important to be clear about the role of the States of Alderney in the strategic planning of, and provision of, care and support services
- travelling to and from appointments in Guernsey and accompaniment for this travel, where necessary, was a concern, as were arrangements for family members visiting relatives in hospital in Guernsey
- the Home Help service, which, in Alderney, is privately funded, was reported to play a key role for Alderney residents with care and support needs
- there were concerns that with younger people leaving the Island there could be less availability of informal care for older residents with care needs
- there was a suggestion that professional services could visit more frequently or that telehealth/telecare services could be arranged to allow more frequent meetings via video-link in between visits to the Island
- there were concerns that benefit rates were based on the cost of living in Guernsey



## PART TWO:

# RESPONSES TO QUESTIONS

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**Note on method:**

All written responses have been categorised thematically and grouped according to which question(s) they related to. Summaries of written responses, therefore, incorporate comments which thematically relate to the question whether or not the comments were submitted in relation to a particular question.

In cases where several options were selected – if responses were contradictory (i.e. ‘agree’ and ‘disagree’ were both selected) - the response to that question was discarded. If they were tied between two options as part of a scale, then the lower option or least supportive option was input (i.e. if ‘agree’ and ‘somewhat agree’ were both selected ‘somewhat agree’ would have been input).

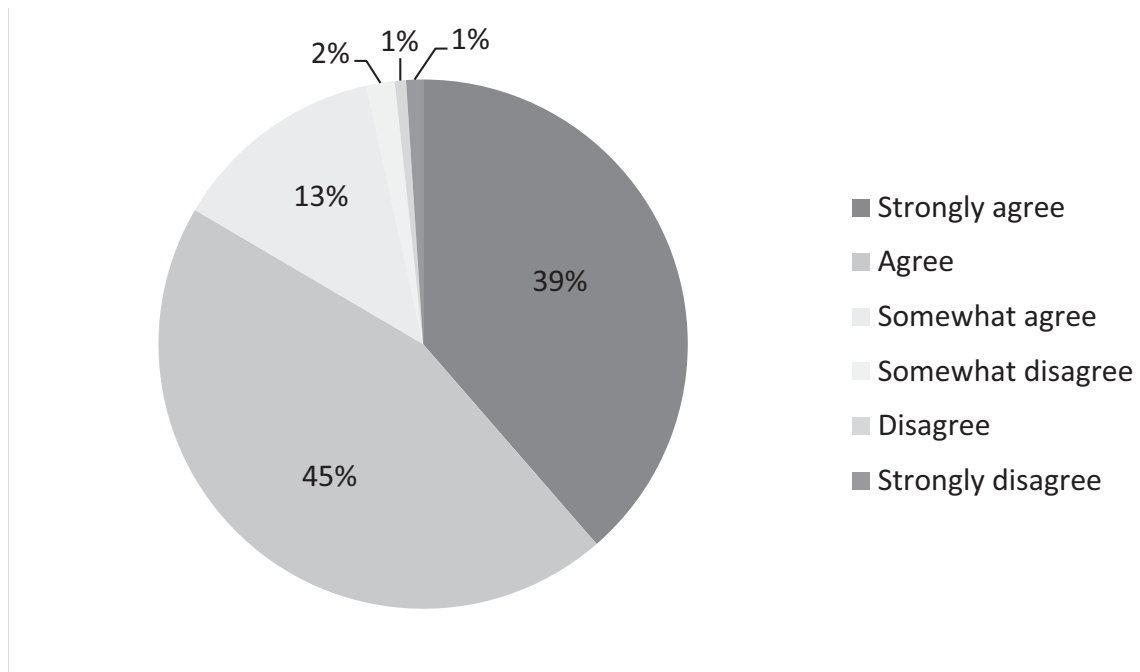
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## Principles

### 1. To what extent do you agree or disagree with the above principles?

The vast majority of respondents (83%) agreed or strongly agreed with the principles. The number of people agreeing or strongly agreeing was higher amongst respondents who were cared for, or worked with, people with care and support needs (88%).

Fewer Alderney respondents (64%) agreed or strongly agreed with the principles.



| Answer Choices    | Responses  |                           |
|-------------------|------------|---------------------------|
|                   | Percentage | Actual no. of respondents |
| Strongly Agree    | 39%        | 112                       |
| Agree             | 45%        | 130                       |
| Somewhat agree    | 13%        | 38                        |
| Somewhat disagree | 2%         | 5                         |
| Disagree          | 1%         | 2                         |
| Strongly disagree | 1%         | 3                         |
| Total respondents |            | 290                       |

## **BOX A – SUPPORTED LIVING AND AGEING WELL STRATEGY PRINCIPLES**

1. Promote, improve and protect individuals' health, wellbeing and dignity.
2. Ensure there are opportunities for independence and choice.
3. Enable fair access to appropriate care and support and suitable housing.
4. Establish a partnership culture whereby the public, private and third sectors<sup>1</sup>, service users and their carers can each contribute to service delivery and developments, and share information appropriately.
5. Have regard to affordability and financial viability for the funders, providers and recipients of care and support services.
6. Ensure that service provision and funding options are sustainable in the medium and long term.
7. Ensure safe, quality care and ensure standards through appropriate regulation.

By pursuing these, the following outcomes should be progressively realised:

- Reduction, where possible, of the incidence of adults (18+) having enduring care, support or supported accommodation needs by, where possible, preventing needs from arising or increasing.
- Improved outcomes for all adults (18+) with enduring care, support or supported accommodation needs.
- Protection of the health and wellbeing of the carers of those with care and support needs.

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## 2. Do you have any comments on these principles?

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### General comments about the principles

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Twelve respondents expressed scepticism about the principles appearing to be 'vanilla' (i.e. bland and easy for everyone to agree with) and highlighted that the interpretation of the principles would be key.

One respondent commented on the fact that they felt the principles were of varying importance and should be weighted differently.

A few respondents were concerned that existing services were not in line with the principles. They and others were sceptical that the principles could in fact be translated into actions. Some suggested that the principles should be about identifying 'adequacy' rather than being aspirational in their intention. Others felt that the outcomes should be clearly defined and measurable.

One respondent felt that the Strategy should include under-18s (whose needs are currently being addressed via the Children and Young People's Plan). Another felt that the scope of the Strategy should not include both older adults and working-age disabled adults as they felt the needs of the two groups were too distinct.

One respondent questioned the process of formulating the principles and felt that disabled and older adults had not been adequately included in this process. Another suggested that the Strategy should be shaped around those with the most complex needs.

### Promote, improve and protect individuals' health, wellbeing and dignity.

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One respondent commented that to achieve dignity would require discrimination legislation equivalent to the UK Equality Act, 2010 and comprehensive diversity and inclusion training. Another commented that they felt dignity was compromised where elderly people were "put with people of varying degrees of learning, mental and socio-economic class."

### Ensure there are opportunities for independence and choice.

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Some respondents were concerned that there were not enough options available to offer choice at the moment, particularly for people with more complex needs, some of whom have their needs met off-Island. Another respondent was concerned that certain levels of choice (e.g. the choice to receive 24/7 care in your own home) would be unaffordable. Some felt that their support for the principle would depend on how independence and choice were interpreted.

A few respondents were concerned about the level of choice being appropriate to a person's capacity to make choice and that individuals would not be appropriately supported in making choices. One respondent felt that there was a risk that some people might find choice stressful or confusing.

Some organisations commented that the principle of choice aligned with the UN Convention on the Rights of Persons with Disabilities. They highlighted the importance of offering people with learning disabilities and people with complex needs choice about where they lived and who they lived with, in order for them to have equal opportunities to 'have a life' compared with other people their age; i.e. that young disabled people should be able to have the same choices as anyone else.

### Enable fair access to appropriate care and support and suitable housing.

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Several respondents felt that if proposals were taken forward to include the value of property in means-tested support for care home accommodation and services this would not amount to 'fair access'. Others were more generally concerned about the interpretation of 'fair'.

### Establish a partnership culture whereby the public, private and third sectors, service users and their carers can each contribute to service delivery and developments, and share information appropriately.

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Several respondents commented on the importance of this principle and the fact that they felt that it was not happening at the moment.

Some respondents were concerned that the principle suggested that the States would shift some of its responsibilities onto the third sector and rely on them too heavily rather than invest in community care. Others felt that States' provision should only be a last resort.

Some concern was raised by Alderney respondents on the lack of capacity in the third sector in Alderney.

One respondent highlighted the importance of partnership working and data sharing with primary care.

Have regard to affordability and financial viability for the funders, providers and recipients of care and support services. Ensure that service provision and funding options are sustainable in the medium and long term.

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One person expressed concern that these principles suggested an intention to withdraw public funding and suggested that raising taxes would be preferable to capping public expenditure.

Ensure safe, quality care and ensure standards through appropriate regulation.

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One respondent highlighted the importance of regulation. Another noted that 'appropriate regulation' should not be too 'heavy'.

#### **General comments about the outcomes of applying the principles**

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- Reduction, where possible, of the incidence of adults (18+) having enduring care, support or supported accommodation needs by, where possible, preventing needs from arising or increasing.
  - Improved outcomes for all adults (18+) with enduring care, support or supported accommodation needs.
  - Protection of the health and wellbeing of the carers of those with care and support needs.
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Two respondents commented that they were concerned about the use of 'where possible' in point one. One respondent was concerned that 'preventing needs from arising or increasing' not be interpreted as a justification for increasing eligibility thresholds.

### Are the principles incomplete?

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The following subjects were also put forward to be considered for explicit inclusion:

- Dying well
- Services being proactive
- Personalisation/person-centred services
- Prevention, recovery and re-enablement
- Addressing lack of financial security of older people
- Helping people to plan for old age
- Spending money efficiently

### Other comments

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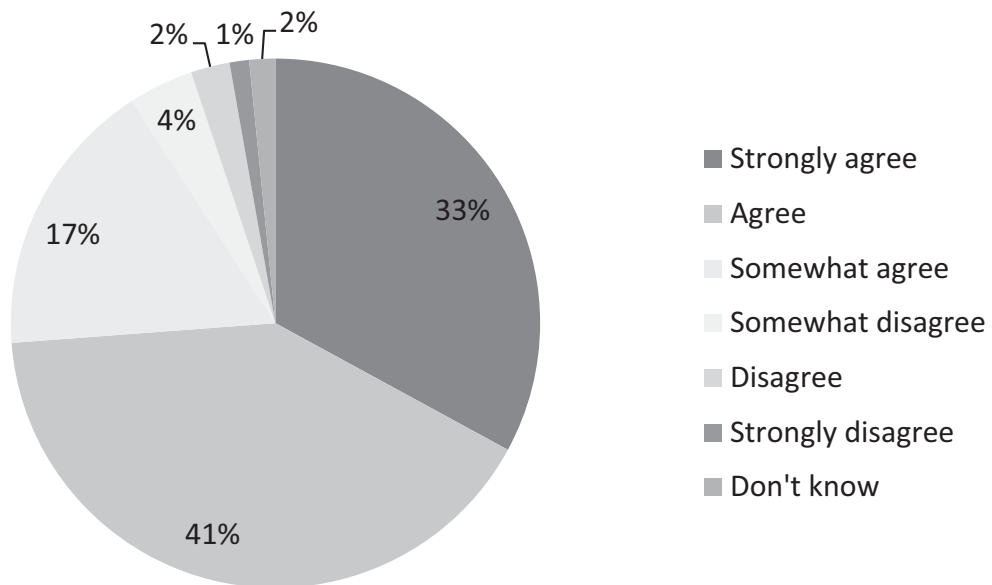
A number of other comments were received which primarily related to funding and service provision rather than the principles. Where appropriate, these have been integrated into the discussion elsewhere.

## The role of the public sector

### 3. To what extent do you agree or disagree that it is the role of the States to be a 'strategic planner'?

A large majority (74%) agreed or strongly agreed that the States should be a 'strategic planner'.

A number of supportive comments were made regarding the role of the States as 'strategic planner'. One Alderney resident asked how this strategic planning would relate to the States of Alderney.



| Answer Choices    | Response   |                           |
|-------------------|------------|---------------------------|
|                   | Percentage | Actual no. of respondents |
| Strongly agree    | 33%        | 83                        |
| Agree             | 41%        | 103                       |
| Somewhat agree    | 17%        | 43                        |
| Somewhat disagree | 4%         | 10                        |
| Disagree          | 2%         | 6                         |
| Strongly disagree | 1%         | 3                         |
| Don't know        | 2%         | 4                         |
| Total respondents |            | 252                       |



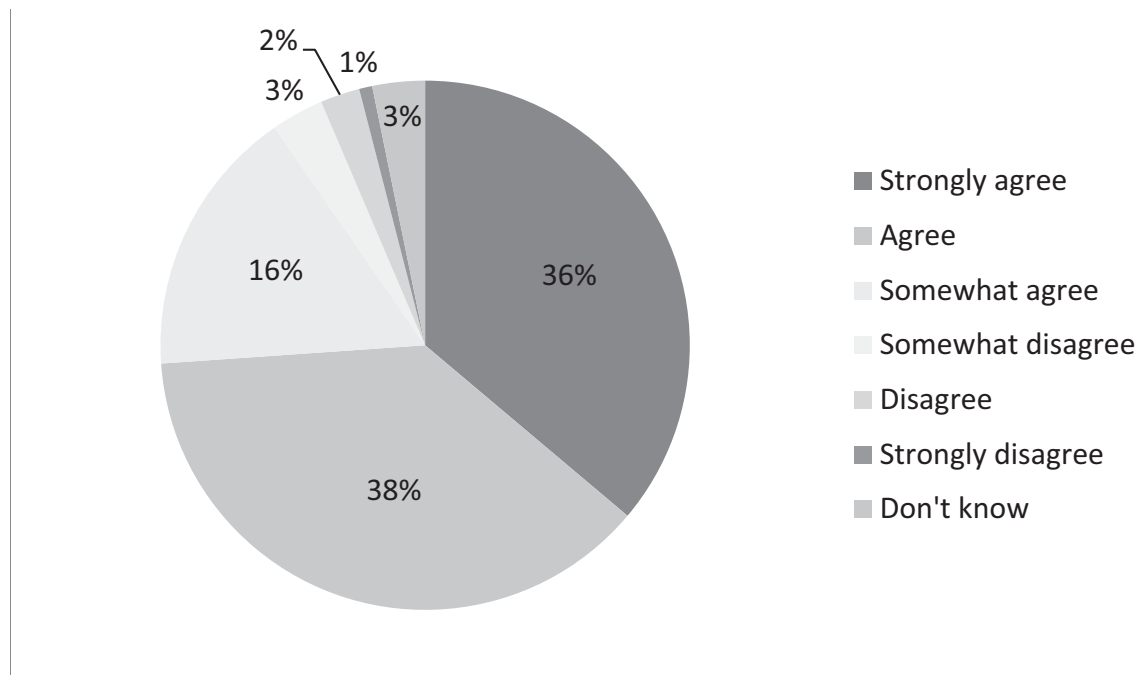
**BOX B – STATES AS STRATEGIC PLANNER**

- Monitoring the number of people in need of care and support, the availability of care and support services, the quality and safety of care and people's satisfaction with the care and support they receive.
- Actively supporting the development of appropriate services where there are not enough existing or where there are problems with safety or quality.
- Coordinating care across the private, public and third sectors and making sure that referrals and links between services work effectively.
- Ensuring information is available so that people can find support when they need it and make informed choices.
- Broadening and developing regulation of all services within the care sector.
- Preventing needs from increasing through health promotion and the promotion of positive attitudes towards disabled people and towards ageing.
- Ensuring strategic management of population, land and education to support growth in the care sector where needed.
- Ensuring that, where possible, the housing stock is built to accessible standards and support to adapt housing to make it more accessible, where this is the best available option, is considered and addressed.

#### 4. To what extent do you agree or disagree with the statement that “the States should be working more closely with the private and third sectors”?

A large majority (74%) agreed or strongly agreed that the States should be working more closely with the private and third sectors. All of the respondents who identified themselves as third sector organisations, private sector professionals or care providers, agreed or strongly agreed.

Fewer Alderney respondents (45%) agreed or strongly agreed that the States should be working more closely with the private and third sectors.



| Answer Choices    | Response   |                           |
|-------------------|------------|---------------------------|
|                   | Percentage | Actual no. of respondents |
| Strongly agree    | 36%        | 90                        |
| Agree             | 38%        | 94                        |
| Somewhat agree    | 16%        | 41                        |
| Somewhat disagree | 3%         | 8                         |
| Disagree          | 2%         | 6                         |
| Strongly disagree | 1%         | 2                         |
| Don't know        | 3%         | 8                         |
| Total respondents |            | 249                       |

Many respondents (including some third and private sector organisations) agreed that there was potential for them to deliver services or support through a partnership approach, and stated that they would welcome working closely with the States in future.

The possibility of working with the third sector to develop a broader befriending service and other community initiatives was suggested.

Some respondents noted that third sector organisations often had access to information about the difficulties people were having and regular contact with some constituents that the public sector did not have, and this made them valuable partners.

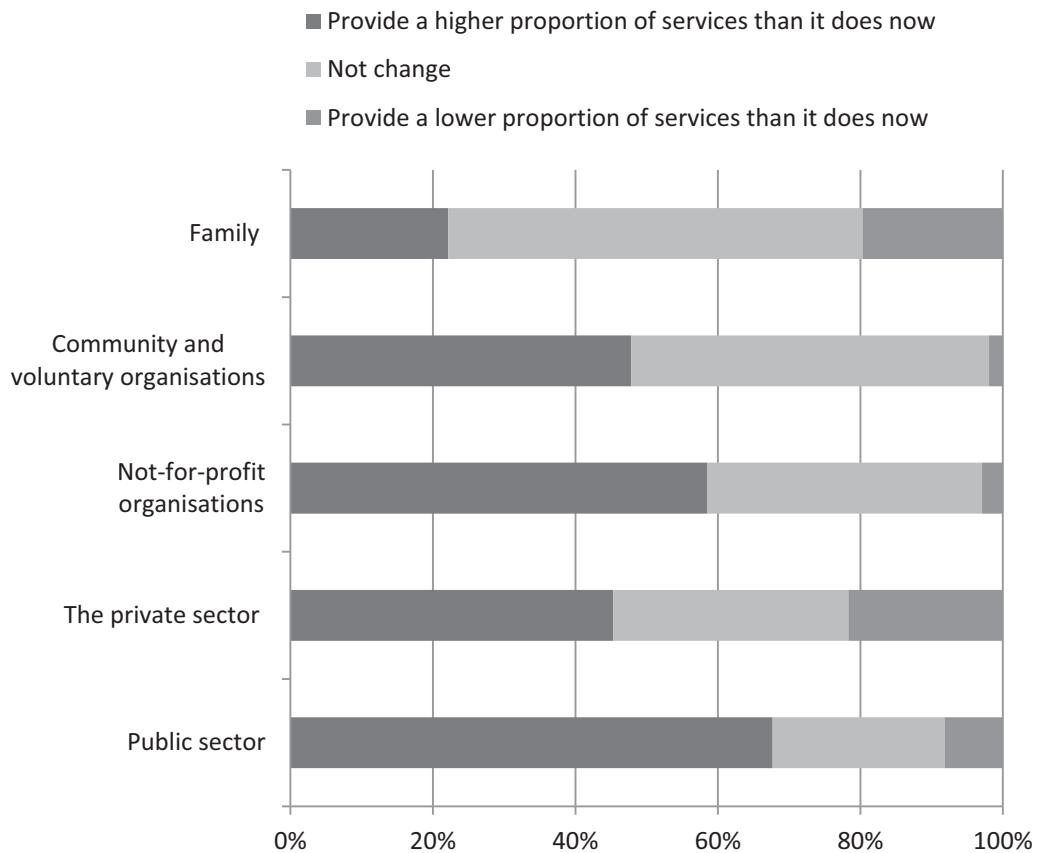
Alderney respondents felt that the States of Alderney should also be part of any partnership working on the Island, though there were some concerns about the capacity of the third sector in Alderney to be a substantial provider.

Some respondents suggested that there needed to be an appropriate level of quality assurance for services provided by the private and third sectors.

## 5. Who should be providing care and support?

More than half of respondents felt that the public and not-for-profit sectors should provide a higher proportion of care and support services than they do at present.

Alderney respondents also expressed majority support for the public sector providing more care and support than they do at present. However, the majority of Alderney respondents did not support the not-for-profit sector increasing provision.



|   | Provide a higher proportion of services than it does now | Not change | Provide a lower proportion of services than it does now | Don't know | Total respondents |
|---|--|------------|---|------------|-------------------|
| <b>Public sector (i.e. the States)</b>                      | 65%<br>157   | 23%<br>56  | 8%<br>19  | 4%<br>10   | 242               |
| <b>The private sector (commercial/for-profit companies)</b> | 41%<br>92  | 30%<br>67  | 20%<br>44   | 9%<br>21   | 224               |
| <b>Not-for-profit organisations</b>                         | 54%<br>120   | 36%<br>79  | 3%<br>6   | 8%<br>18   | 223               |
| <b>Community and voluntary organisations</b>                | 44%<br>99  | 46%<br>104 | 2%<br>4   | 8%<br>18   | 225               |
| <b>Family</b>   | 20%<br>45  | 52%<br>118 | 18%<br>40   | 10%<br>23  | 226               |

A few people indicated that identifying who should provide services was less important than ensuring that services are provided to a good quality: "I don't care who provides these services as long as somebody does and they do it well."

Some respondents suggested that whilst more should be done to support family carers, there should not be an expectation that families would increase the proportion of care that they provided. An Alderney respondent was particularly concerned about the impact that emigration of younger family members was having on the availability of informal care.

Some respondents suggested that the range of services provided by the private sector could expand but this would require some support and partnership working with the States.

Some concerns were noted about profit motivations in the private sector and some felt that there should be more public sector provision of care homes and social housing for people with care and support needs.

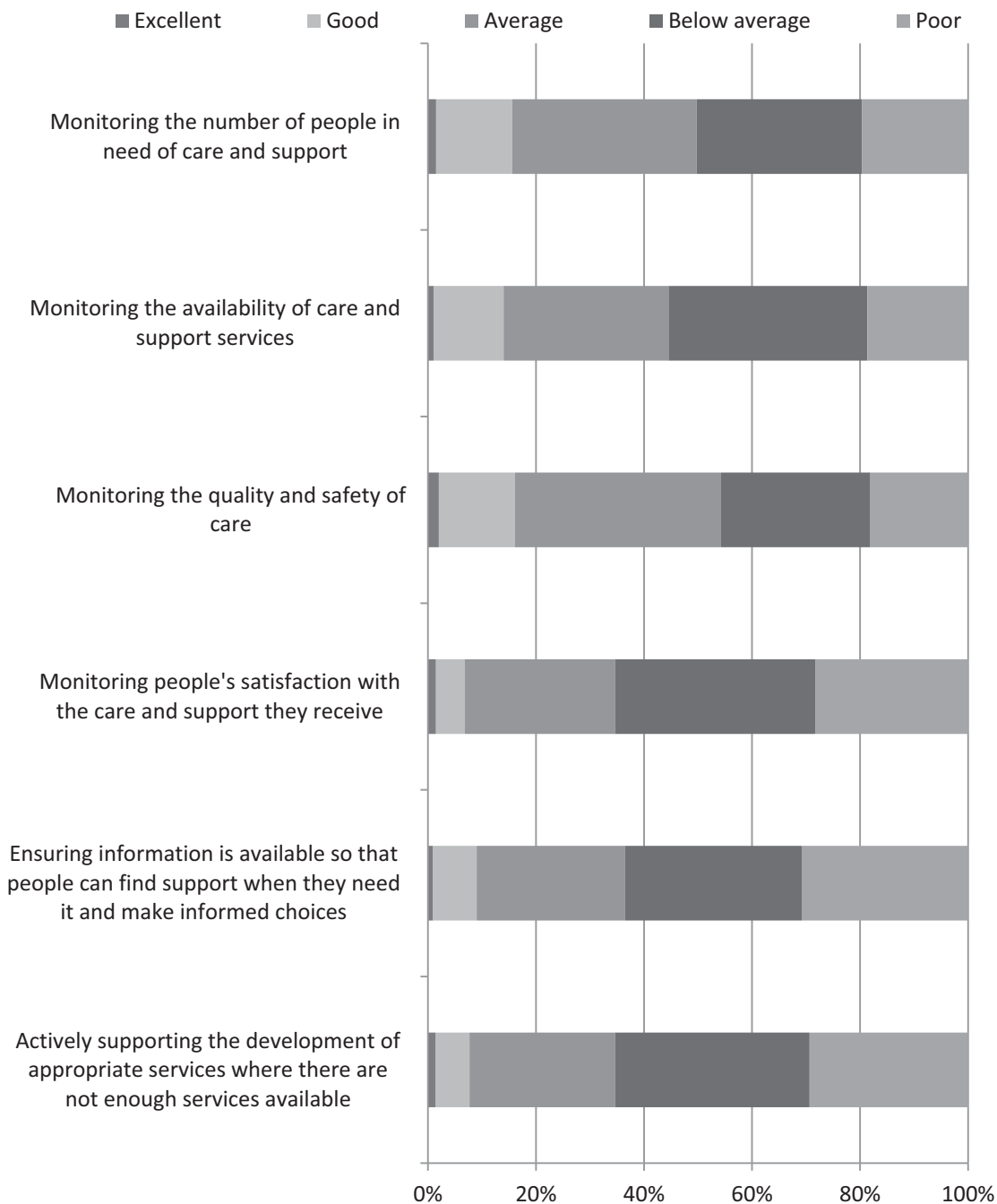
Others felt unable to answer because they felt that the most appropriate sector to provide services would depend on what the nature of the specific services were.

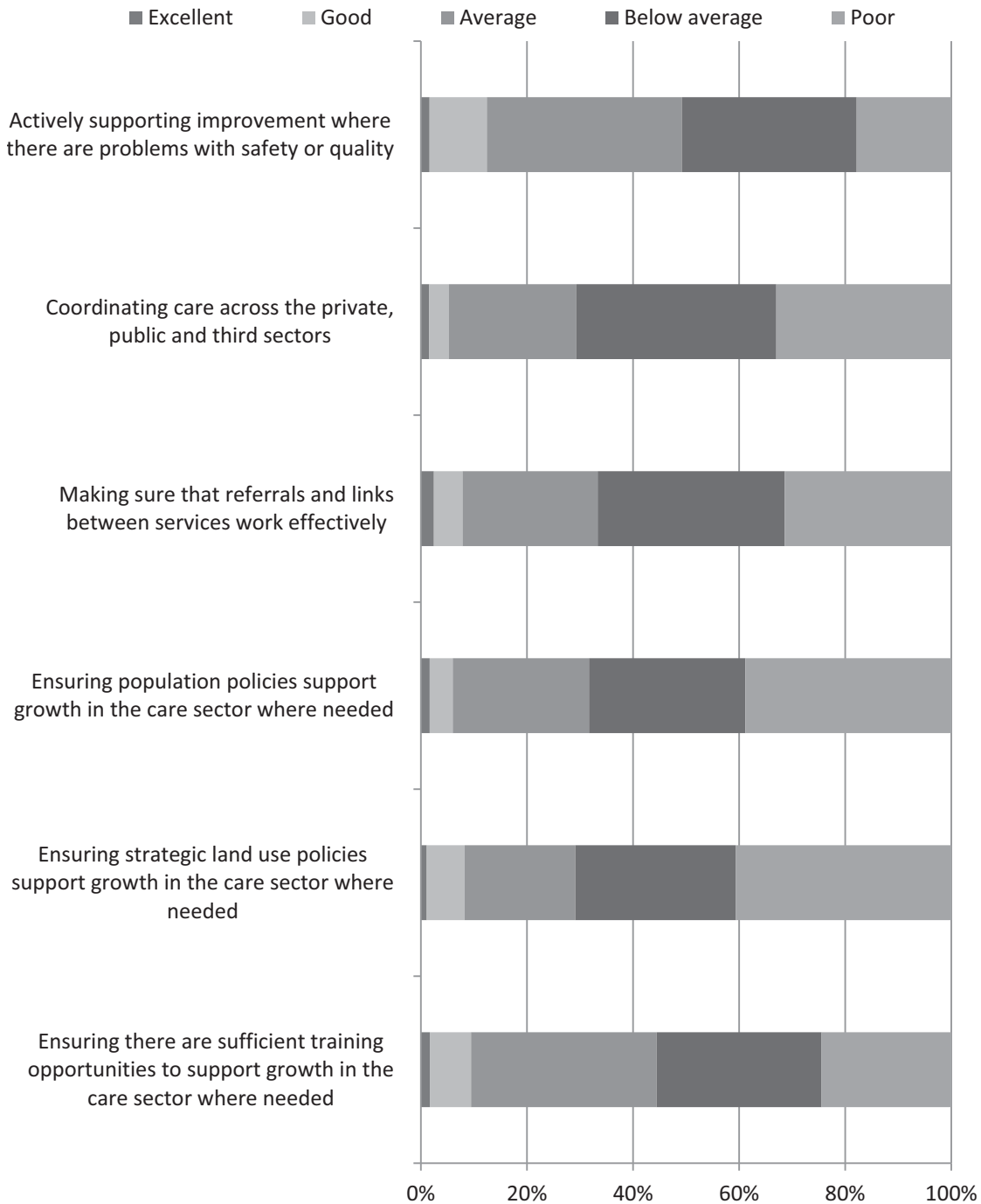
Concerns were raised about responsibility for service provision being moved from the public sector to other sectors without the accompanying funding streams.

There were concerns about relying too much on the third sector and also about the capacity of the third sector in Guernsey to increase the number of 'not-for-profit' service providers, when many existing organisations were only community groups at present.

## 6. From your experience, how well do you think the States currently performs in the following?

Where they expressed a view, about half of respondents felt that the States' performance was either "below average" or "poor" for the majority of the areas considered.









|   | Excellent | Good      | Average   | Below average | Poor      | Don't know / no experience | Total |
|---|-----------|-----------|-----------|---------------|-----------|----------------------------|-------|
| Monitoring the number of people in need of care and support   | 1%<br>3   | 11%<br>28 | 28%<br>68 | 25%<br>61     | 16%<br>39 | 19%<br>47                  | 246   |
| Monitoring the availability of care and support services  | 1%<br>2   | 10%<br>25 | 24%<br>59 | 29%<br>71     | 15%<br>36 | 21%<br>50                  | 243   |
| Monitoring the quality and safety of care   | 2%<br>4   | 12%<br>28 | 31%<br>76 | 23%<br>55     | 15%<br>36 | 18%<br>43                  | 242   |
| Monitoring people's satisfaction with the care and support they receive                                       | 1%<br>3   | 4%<br>11  | 23%<br>57 | 30%<br>76     | 24%<br>58 | 16%<br>40                  | 245   |
| Ensuring information is available so that people can find support when they need it and make informed choices | 1%<br>2   | 7%<br>17  | 24%<br>58 | 28%<br>69     | 27%<br>65 | 14%<br>33                  | 244   |
| Actively supporting the development of appropriate services where there are not enough services available     | 1%<br>3   | 5%<br>13  | 23%<br>56 | 31%<br>75     | 25%<br>61 | 15%<br>36                  | 244   |
| Actively supporting improvement where there are problems with safety or quality                               | 1%<br>3   | 8%<br>20  | 28%<br>68 | 25%<br>61     | 13%<br>33 | 24%<br>60                  | 245   |
| Coordinating care across the private, public and third sectors  | 1%<br>3   | 3%<br>7   | 19%<br>46 | 30%<br>72     | 26%<br>63 | 21%<br>52                  | 243   |
| Making sure that referrals and links between services work effectively  | 2%<br>5   | 5%<br>11  | 21%<br>52 | 30%<br>72     | 26%<br>64 | 16%<br>40                  | 244   |
| Ensuring population policies support growth in the care sector where needed                                   | 1%<br>3   | 3%<br>8   | 19%<br>47 | 22%<br>54     | 29%<br>71 | 25%<br>60                  | 243   |
| Ensuring strategic land use policies support growth in the care sector where needed                           | 1%<br>2   | 5%<br>13  | 16%<br>38 | 23%<br>55     | 30%<br>74 | 25%<br>61                  | 243   |
| Ensuring there are sufficient training opportunities to support growth in the care sector where needed        | 1%<br>3   | 6%<br>14  | 26%<br>63 | 23%<br>56     | 18%<br>44 | 27%<br>65                  | 245   |

|  | Excellent | Good      | Average   | Below average | Poor      | Don't know / no experience | Total |
|--|-----------|-----------|-----------|---------------|-----------|----------------------------|-------|
| Regulation of care services to ensure safety and quality       | 2%<br>4   | 12%<br>29 | 25%<br>61 | 18%<br>44     | 18%<br>43 | 25%<br>60                  | 241   |
| Supporting people to adapt houses                              | 2%<br>5   | 7%<br>17  | 20%<br>49 | 23%<br>56     | 23%<br>57 | 24%<br>59                  | 243   |
| Ensuring new buildings have minimum standards of accessibility | 3%<br>8   | 16%<br>39 | 30%<br>73 | 16%<br>39     | 8%<br>18  | 26%<br>63                  | 240   |
| Preventing needs from increasing through health promotion      | 2%<br>6   | 14%<br>35 | 39%<br>95 | 23%<br>56     | 10%<br>24 | 11%<br>27                  | 243   |
| Promoting positive attitudes towards disabled people           | 3%<br>7   | 16%<br>38 | 36%<br>87 | 23%<br>56     | 12%<br>28 | 10%<br>23                  | 239   |
| Promoting positive attitudes towards ageing                    | 2%<br>6   | 12%<br>28 | 29%<br>71 | 28%<br>67     | 19%<br>47 | 10%<br>24                  | 243   |

Respondents raised particular concerns about:

- **The provision of information and advice** (around 15 comments)
  - It was suggested that there would be value in having a key point of contact who could provide advice about the range of services for people, and that this might benefit from being in a physical location which was accessible to older people.
  - There were concerns that information was hard to come by, or hard to find or access.
  - Organisations were concerned that people were unaware that there was help available, or how to begin to find out about or access it.
  - Some felt that ensuring information was available in hard copy would also be important since many older people may not look on websites.
  - Ensuring that there was information about the available range of social and community activities so that people could pursue their interests was recognised as important.
  - A single point of contact for care coordination, who could also help with information access, was suggested.
- **Data management**
  - The importance of having information on present and future need levels and information about what people wanted from care and support was highlighted as important to the third and private sectors as well as the public sector.
  - Other respondents noted the importance of robust, data protection compliant information sharing for identifying disease prevalence and sharing patient data between different health and social care professionals and organisations. They also raised concerns about data sharing and data protection issues when working with volunteer and community organisations.
- **Care quality and regulation**
  - Some respondents noted the importance of improving adult safeguarding.
  - Whilst some respondents noted that care homes were already regulated, there was support for universal regulation including regulation of domiciliary care services and States-run facilities.
  - One respondent commented on the need to enforce police checks on domiciliary care staff.
  - It was felt that the focus of regulation should be on interactions with residents and quality of life.

- **Building management**

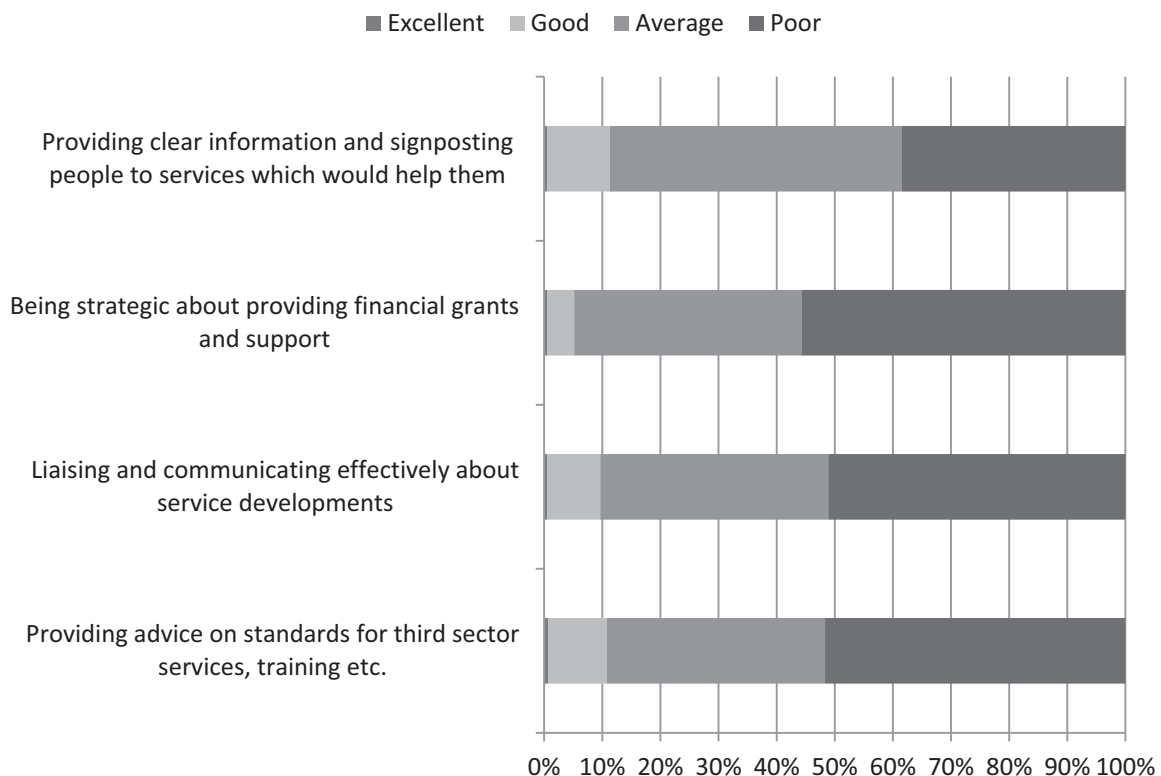
- One respondent raised concerns about the quality of care accommodation and the lack of purpose-built facilities.
- One respondent was concerned about the Environment Department refusing adaptations to allow vehicular access to some properties.

- **Bureaucracy**

- A couple of respondents raised concerns about 'bureaucracy' and found that some of the forms or application processes for care services or benefits were difficult to complete without assistance.
- Some concerns were also raised about:
  - lack of strategic planning and clarity of role,
  - weak leadership,
  - poor governance and financial management,
  - silo working (conscious and unconscious),
  - over-reliance on a few key individuals,
  - skills shortages, shortages in skill development.

## 7. How effectively do you think that the States supports third sector organisations (including not-for-profit organisations, charities, community and voluntary organisations) in the following respects so that they can use their resources to maximum effect in relation to the provision of long-term care services?

Over half of respondents felt that the States' support to third sector organisations was poor in all respects listed, apart from providing clear information and signposting people to services which would help them, where just over half of respondents felt that the States support to third sector organisations was average. However, out of those respondents who identified themselves as third sector community organisations, more than half felt that performance was poor in all areas with only one respondent (out of twenty six) rating any of the areas higher than 'average'.



|  | <b>Excellent</b> | <b>Good</b>      | <b>Average</b>    | <b>Poor</b>      | <b>Total</b> |
|--|------------------|------------------|-------------------|------------------|--------------|
| Providing clear information and signposting people to services which would help them | 1%<br><i>1</i>   | 11%<br><i>22</i> | 50%<br><i>101</i> | 39%<br><i>78</i> | <i>202</i>   |
| Being strategic about providing financial grants and support                         | 1%<br><i>1</i>   | 5%<br><i>8</i>   | 39%<br><i>68</i>  | 56%<br><i>97</i> | <i>174</i>   |
| Liaising and communicating effectively about service developments                    | 1%<br><i>1</i>   | 9%<br><i>16</i>  | 39%<br><i>68</i>  | 51%<br><i>90</i> | <i>175</i>   |
| Providing advice on standards for third sector services, training etc.               | 1%<br><i>1</i>   | 10%<br><i>15</i> | 38%<br><i>56</i>  | 52%<br><i>77</i> | <i>149</i>   |

Some respondents raised concerns about what they thought the States did/didn't see its role being at present and whether it was equipped to undertake this kind of role: "Does it have the skills and experience to do this? What does it mean? Is it simply trying to "save money" by getting services provided by charities and volunteers for free?"

Concerns were also raised by some respondents about the current working relationship with the third sector and the need for genuine partnership in developing services and service specification, rather than co-working being seen as a top-down commissioning practice. The need for the States to nurture third-sector service development in some areas was also suggested.

A few respondents raised concerns about the level of communication within the States and between the States and key partners.

One respondent commented that they felt that third sector organisations could get standards and training from within their own 'regulatory bodies' (or presumably, where they are branches of national organisations from their headquarters).

Another respondent raised concerns about the level of understanding within the States of the needs of disabled people.

It was suggested that the States could better support charitable organisations by assisting with Guernsey Vetting Bureau checks, support with managing data protection, information and training.

As with question 5, some respondents were concerned about the possibility of the States trying to move service provision to the third sector without appropriate funding streams.

One respondent raised concerns about the extent to which charitable organisations were funding equipment provision.

Alderney respondents felt that the States of Alderney was not proactively involved in the areas mentioned in this question.

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## 8. Do you have any relevant evidence or experiences you would like to share with us relating to the role of the States in care and support provision? Do you have any further comments about the role of the public sector?

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Responses to the question were wide-ranging. The three most frequent themes for this topic were:

- **Difficulty obtaining information and advice** about the care, support and funding available (see question 6 above)
- **Poor coordination** of services (see question 15 below)
- **Under-resourcing of community services** (see question 11 below)

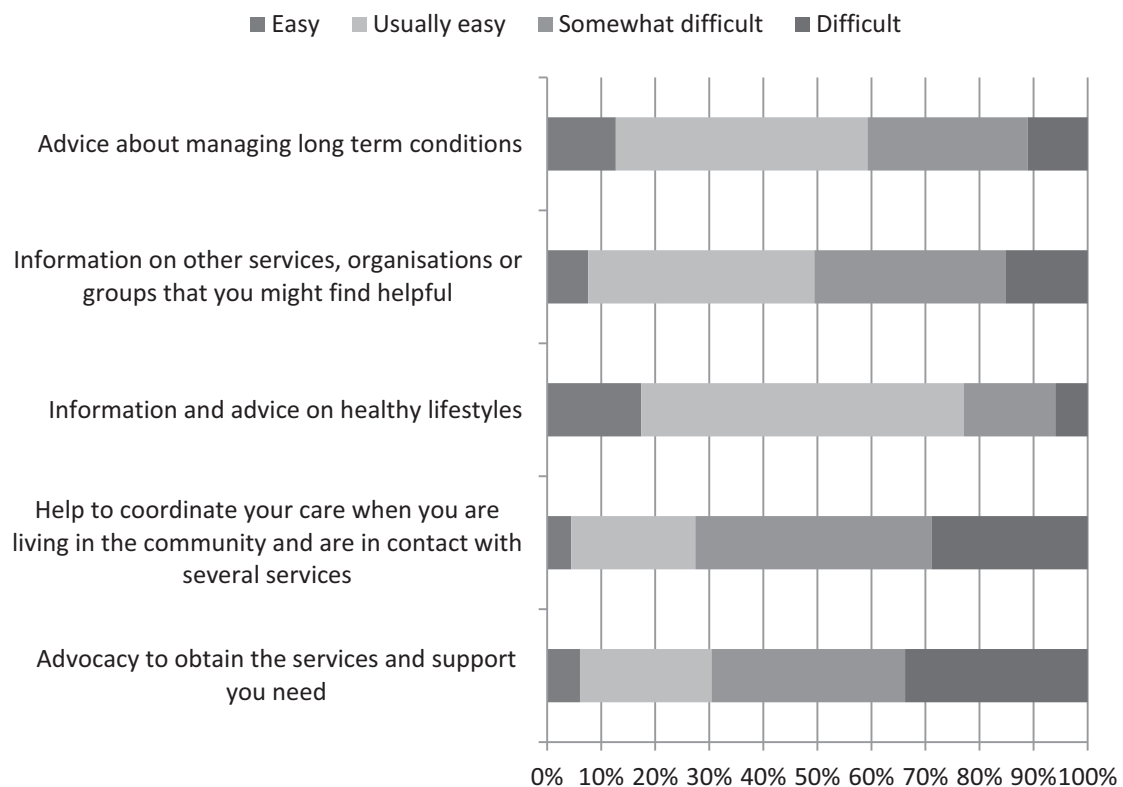
Relatively few comments were made which did not relate to any of the questions asked above (in which case those comments have been incorporated into those other questions). Some concerns were raised about there being too much focus on redeveloping facilities and not enough on adequate staffing or service provision.



## A different way to deliver services

### 9. At the moment how easy or difficult is it to obtain the following services from the primary care practitioners you are in regular contact with?

The majority of respondents found that it was usually easy to obtain advice about healthy lifestyles and managing long term conditions. However, a significant minority reported difficulty obtaining information about managing long term conditions. A majority reported some difficulty with finding help with advocacy and care coordination within the current system – these roles are not clearly designated to any particular group of primary care practitioners at present.



|   | <b>Easy</b> | <b>Usually easy</b> | <b>Somewhat difficult</b> | <b>Difficult</b> | <b>Don't know</b> | <b>Total</b> |
|---|-------------|---------------------|---------------------------|------------------|-------------------|--------------|
| <b>Advice about managing long term conditions</b>   | 10%<br>24   | 38%<br>88           | 24%<br>56                 | 9%<br>21         | 18%<br>41         | 230          |
| <b>Information on other services, organisations or groups that you might find helpful</b>                         | 6%<br>14    | 34%<br>77           | 28%<br>65                 | 12%<br>28        | 20%<br>45         | 229          |
| <b>Information and advice on healthy lifestyles</b>   | 15%<br>35   | 52%<br>120          | 15%<br>34                 | 5%<br>12         | 12%<br>28         | 229          |
| <b>Help to coordinate your care when you are living in the community and are in contact with several services</b> | 3%<br>6     | 13%<br>31           | 26%<br>59                 | 17%<br>39        | 41%<br>95         | 230          |
| <b>Advocacy to obtain services and support you need</b>   | 4%<br>9     | 16%<br>36           | 23%<br>53                 | 22%<br>50        | 35%<br>81         | 229          |

There were a number of comments received on the role of GPs. Most of the comments recognised the role of GPs as key to supporting people better in the community, but most people did not support the suggestion that GPs should be key case coordinators for individuals – they felt that this was an important role for another kind of primary care professional, though a need to work closely with GPs was recognised. In some cases third sector organisations had taken on advocacy (and coordination) roles for people in the community. There were also suggestions that people living in the community would benefit from more GPs who were subject specialists in managing particular conditions. A few commented on concerns about the cost of GP consultations, though one person stated that they would prefer to pay than experience long waiting times for appointments.

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**10. Have you been in contact with community or hospital-based services in the last ten years? This could be on behalf of yourself or on behalf of someone you care for. (e.g. Community Services, Disability Services, Mental Health Services, Older Adult Mental Health Services, care homes, nursing agencies, Duchess of Kent)**

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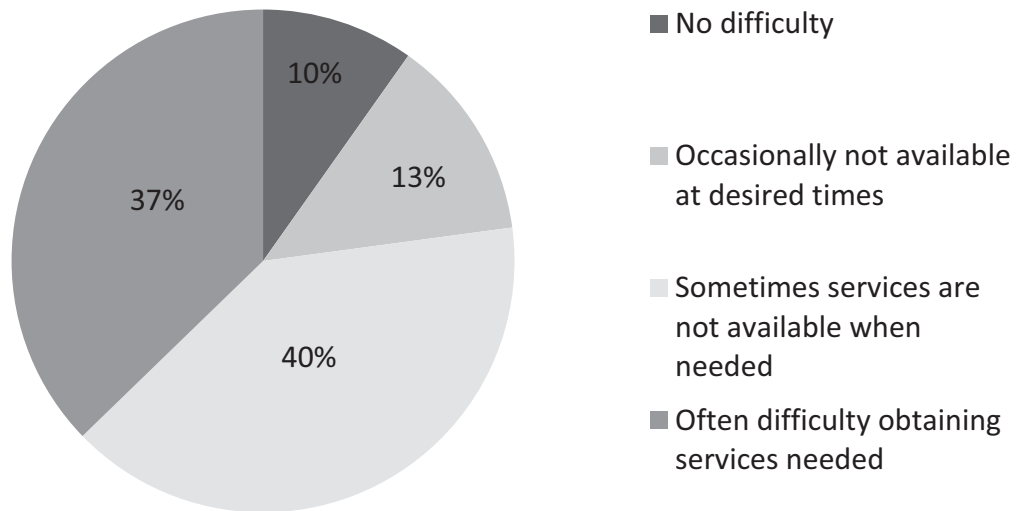
*Number of respondents who answered this question: 234*

The majority of respondents who answered the question (75%) had been in contact with community or hospital-based services in the last ten years.

Fewer Alderney respondents (55%) had been in contact with community or hospital-based services in the last ten years.

This question was largely used to identify the relevance of answers to the following questions on service experience.

## 11. From your experience how easy or difficult is it to access community based services where needed?



The vast majority of respondents (77%) either sometimes or often had difficulty accessing community based services when needed.

|                               | No difficulty | Occasionally not available at desired times | Sometimes services are not available when needed | Often difficulty obtaining services needed | Total respondents |
|-------------------------------|---------------|---|--|--|-------------------|
| <b>Percentage</b>             | 10%           | 13%   | 40%  | 37%  |                   |
| <b>Actual no. respondents</b> | 15            | 20  | 61   | 57   | 153               |

An error resulted in this question being repeated as question 12 – responses were similar:

|                               | <b>No difficulty</b> | <b>Occasionally not available at desired times</b> | <b>Sometimes services are not available when needed</b> | <b>Often difficulty obtaining services needed</b> | <b>Total respondents</b> |
|-------------------------------|----------------------|--|---|---|--------------------------|
| <b>Percentage</b>             | 6%                   | 18%  | 39%   | 36%   |                          |
| <b>Actual no. respondents</b> | 9                    | 27   | 57  | 53  | 146                      |

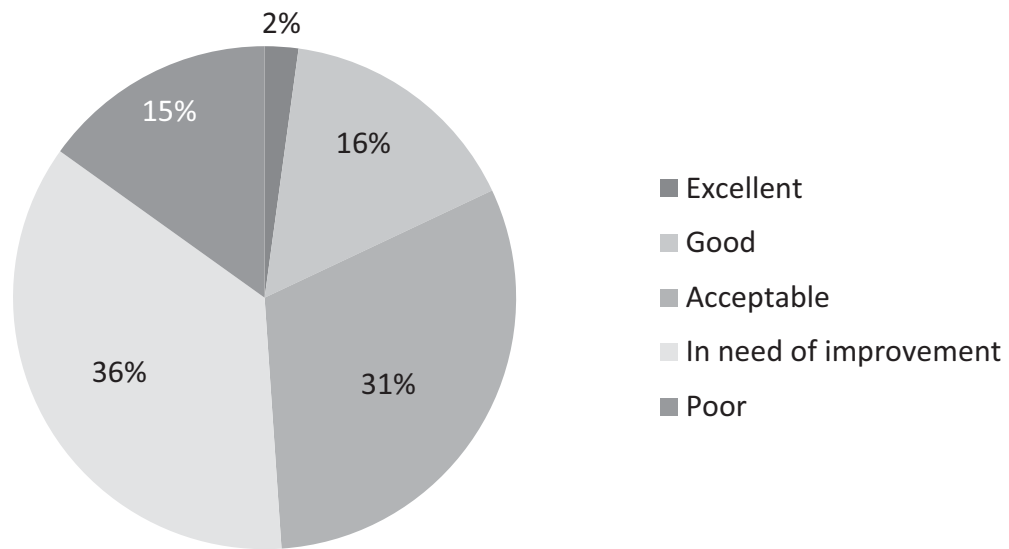
The following comments were made:

- “community services are stretched and cannot respond quickly enough to cases”
- “calls not long enough to meet individual needs”
- “Guidance where to go out of hours is confusing”/“not enough staff or availability especially at weekends”
- “Adequate support usually depends on patients or family members being able to question the system in place and chase up if things do not progress”
- Some respondents reported issues with not having any control over when staff would visit them or being given times to expect staff in order to plan their day.
- Concerns were raised that community services were not person-centred and were often not able to assist people to participate in society, only to get up, eat etc.
- Some respondents commented on the need for a clearly communicated care plan.
- A few respondents were concerned about waiting lists.
- Some respondents felt that individuals needing care felt guilty asking for it because of the limited resources available; and others that staff had inappropriately referred them elsewhere because of lack of availability of the type of care they felt they needed.
- The lack of re-enablement services was noted by some.
- A number of respondents expressed the wish to be able to continue living in their own homes and receive community services there.

### 13. In your experience, how well coordinated is discharge from hospital?

Around half (51%) of respondents felt that their experience of hospital discharge was poor or in need of improvement.

Equal numbers of Alderney respondents (33%) had a good, poor or in need of improvement experience of their discharge from hospital.



|                               | Excellent | Good | Acceptable | In need of improvement | Poor | Total respondents |
|-------------------------------|-----------|------|------------|------------------------|------|-------------------|
| <b>Percentage</b>             | 2%        | 16%  | 31%        | 36%                    | 15%  |                   |
| <b>Actual no. respondents</b> | 3         | 22   | 50         | 50                     | 21   | 139               |

Respondents commented on:

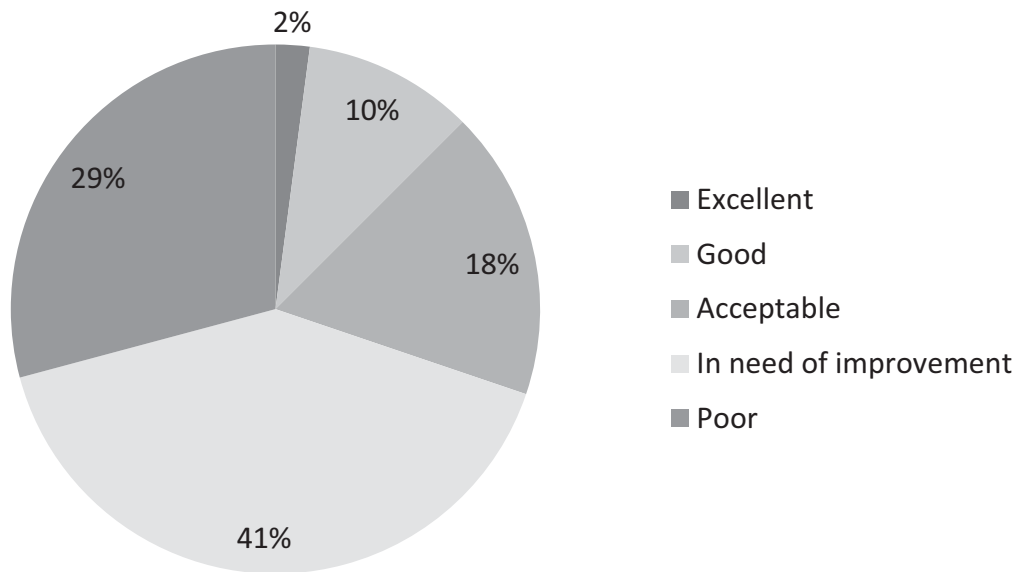
- The necessity for a joined up approach.
- The lack of intermediate care options available (i.e. short term placements in care homes or extra-care facilities to enable people to leave hospital and continue to rehabilitate before going home).
- Concerns that people were being discharged without ensuring that they had the appropriate support at home, food or heating.
- Lack of communication between the UK and Guernsey, and Guernsey and Alderney, at times when an individual was moving following discharge.

- Lack of availability of community services, care homes or other long term placements significantly delaying discharge.

#### 14. If you have experience of obtaining care or support from Community Services or the hospital for someone with mental health issues (including dementia), how easy was it for you to get access?

The majority of respondents (70%) felt that their experience of obtaining care or support from community services or the hospital for someone with mental health issues was in need of improvement or poor.

All Alderney respondents felt that their experience of obtaining care or support from Community Services or the hospital for someone with mental health issues was in need of improvement or poor.

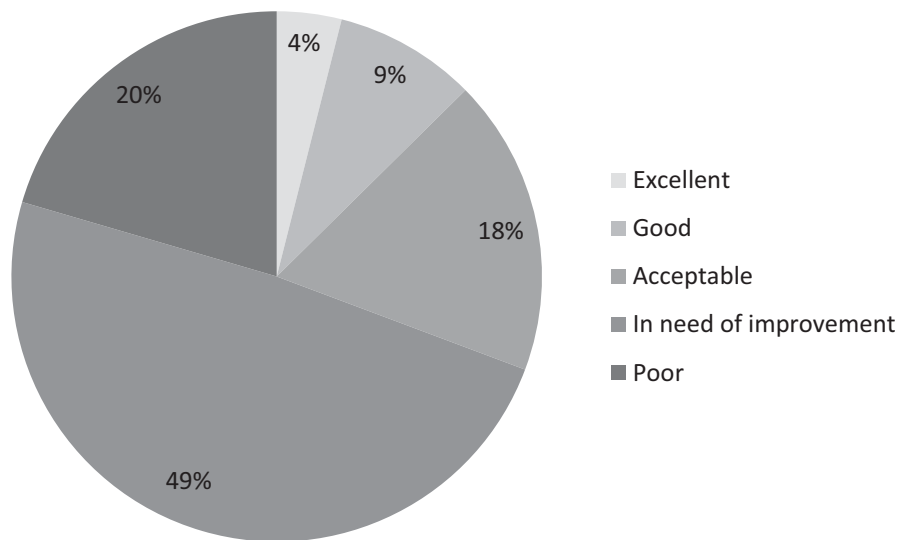


|                               | Excellent | Good | Acceptable | In need of improvement | Poor | Total respondents |
|-------------------------------|-----------|------|------------|------------------------|------|-------------------|
| <b>Percentage</b>             | 2%        | 10%  | 18%        | 41%                    | 29%  |                   |
| <b>Actual no. respondents</b> | 2         | 10   | 17         | 39                     | 28   | 96                |

## 15. Where receiving support from multiple services, how well coordinated was the support you received?

The majority of respondents (69%) felt that the coordination of the support they received from multiple agencies was in need of improvement or poor.

All Alderney respondents felt that the coordination of the support they received from multiple agencies was in need of improvement or poor.



|                               | Excellent | Good | Acceptable | In need of improvement | Poor | Total respondents |
|-------------------------------|-----------|------|------------|------------------------|------|-------------------|
| <b>Percentage</b>             | 4%        | 9%   | 18%        | 49%                    | 20%  |                   |
| <b>Actual no. respondents</b> | 5         | 11   | 23         | 62                     | 26   | 127               |

Many people expressed the desire for a clear, single point of contact to help to coordinate care for individuals and their carers.



In Alderney, coordination between services in Alderney and Guernsey, particularly where travel was involved, raised concerns.

Lack of central information and clear communication left people seeking information or advice confused, with mixed messages from different services.

Carers reported experiencing difficulties trying to coordinate different parts of community services.

There were concerns about lack of consistency of personnel leading to communication and coordination issues.

Respondents felt that they had to fit in with services, rather than services supporting them.

The importance of assessing people as individuals, rather than providing generic responses, was noted by several respondents.

The need to repeat medical history due to lack of record sharing was commented on by some respondents.

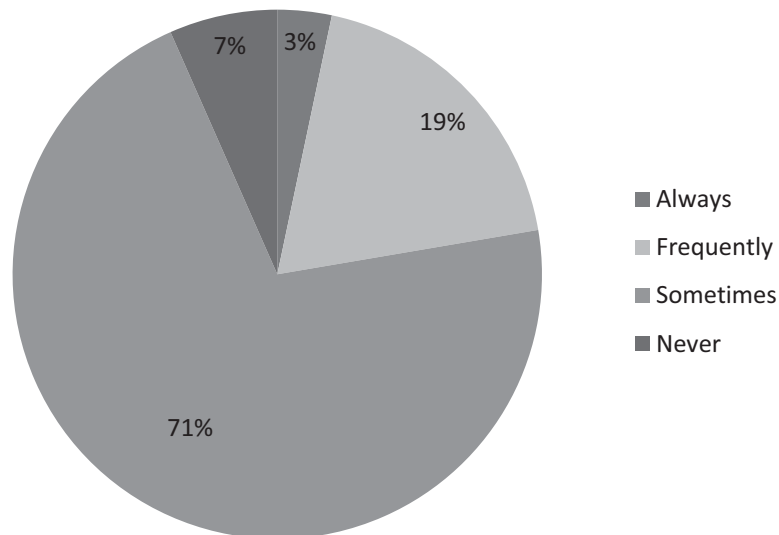
The need for coordination of data sharing in order to better understand public health issues and disease prevalence was also noted.

Some respondents reported having to wait a long time to be seen or visited by certain types of professionals.

## 16. From your experience, do existing services provide you with the support you need to live in a way which is meaningful to you?

The vast majority of respondents (78%) felt that existing services sometimes or never provided them with the support needed to live in a way which was meaningful to them.

All Alderney respondents felt that existing services sometimes or never provided them with the support needed to live in a way which was meaningful to them.



|                               | Always | Frequently | Sometimes | Never | Total respondents |
|-------------------------------|--------|------------|-----------|-------|-------------------|
| <b>Percentage</b>             | 3%     | 19%        | 71%       | 7%    |                   |
| <b>Actual no. respondents</b> | 4      | 23         | 86        | 8     | 121               |

Several comments were made about the fact that services seemed to be provided based on service structure or time limitations rather than shaped around people.

Others commented that support needed to be shaped by individuals' interests and personalities and not be overly generic.

Some Alderney respondents were concerned that they felt support to live in a meaningful way was provided by the private and third sector rather than the public sector in Alderney.

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## **17. Do you have any further comments, evidence or experiences you would like to share with us about the way that services are structured and their coordination?**

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There was some support for the idea of 'single assessments', although it was felt that further thought needed to go into who would be involved in these assessments and how they would be implemented.

There was appreciation for the existing specialist nurses and a desire for expansion of the range of specialist nurses available.

Concerns raised about extra-care housing included:

- The view that mixing of different ages and of groups of people with different kinds of care needs on similar sites could be inappropriate.
- That extra-care would create 'ghettos' of people with care needs.
- That they were not suitable for people with dementia.
- That it would be better to support people in their own homes.
- That extra-care was perceived to offer fewer activities, more isolation and less motivation to be involved in the community of individuals living on the site compared with residential care.
- That it was felt by one resident that outreach to the supported housing from the extra-care schemes was not working adequately.

Other respondents felt that extra-care housing had represented a significant improvement in the range of services available.

Some respondents felt there to be a need for a dementia extra-care facility.

Some respondents felt that there needed to be a clear policy established whereby there was a specified limit to the amount of community care someone could receive (e.g. the number of visits per day) and after that limit is reached supported housing or care homes would be the preferred care setting.

There were concerns that the assessment criteria had/would become stricter as demand for services increased.

There were concerns that care in the community would lead to higher levels of loneliness than care in sheltered or supported housing or care homes.

It was highlighted that support at home could be particularly important for younger disabled people who needed to maintain work and family responsibilities.

The importance of providing people with disabilities with choice about where they lived and who they lived with was highlighted.

It was felt that adequate staffing of community services would be required to underpin any wider changes the Strategy attempted to achieve.

There were concerns that there were insufficient care home beds.

There was a desire for more re-enablement services to be offered.

## The range of services

**18. How important do you think the following would be to people with dementia and their carers? Please rank according to importance from 1 to 6 with 1 being the highest of importance.**

### Overall weighted ranking for data sets

|   | <b>Set A</b>                          | <b>Set B</b>                          | <b>Set C</b>                  | <b>Set D</b>                  |
|---|---------------------------------------|---------------------------------------|-------------------------------|-------------------------------|
| Improved early diagnosis and intervention   | 1st                                   | 1st                                   | 1st                           | 1st                           |
| An increase in specialist community personal care and support services for people with dementia   | 2nd                                   | 2nd/3rd                               | 2nd                           | 2nd                           |
| Improved professional awareness and understanding of dementia   | 3rd                                   | 2nd/3rd                               | 4th                           | 4th                           |
| Good quality information and advice for those with diagnosed dementia and their carers  | 4th                                   | 4th                                   | 3rd                           | 3rd                           |
| An increase in specialist dementia support in care homes or supported housing   | 5th                                   | 5th                                   | 5th                           | 5th                           |
| Further development of support and learning networks so that people with dementia and their carers can talk to and learn from other people who have experienced the same issues | 6th                                   | 6th                                   | 6th                           | 6th                           |
| <i>Total respondents</i>  | <i>16</i>                             | <i>23</i>                             | <i>177</i>                    | <i>184</i>                    |
| <i>Source</i>   | <i>Paper &amp; text response only</i> | <i>Paper &amp; text response only</i> | <i>Incl. online responses</i> | <i>Incl. online responses</i> |

Whilst 206 respondents submitted responses to the question, most of whom did not report problems with the system, 12 respondents reported technical problems with the response on surveymonkey and experienced difficulty assigning the rankings that

they wished to assign. It is possible that others submitting via surveymonkey had similar problems but did not tell us, in which case there is some uncertainty over whether the surveymonkey responses are accurate representations of people's views.

Around ten respondents wished to rank all of the options as '1' believing all of the options to be of importance and seven further respondents wished to assign weightings rather than ranks with several options being assigned the same number (e.g, 1,2,1,3,3,1).

Consequently, in order to give consideration to the reliability of data and the varied approaches to responding, four data sets have been compared and analysed:

- One data set (Set A), which included only written responses that have not encountered technical difficulties, or where the ranking order was stated in free text in surveymonkey. Only responses which were ranked 1, 2, 3, 4, 5, 6 and 7 were taken as valid. This amounted to 16 responses.
- A second data set (Set B), which included only written responses that have not encountered technical difficulties, or where the ranking order was stated in the free text in surveymonkey. This incorporated cases where individuals had ranked several options as 1 etc. into the weighting. This incorporated a further 7 responses bringing the total to 23.
- A third data set (Set C), which included all responses except those that explicitly stated that they had experienced difficulties, but only including responses where they were ranked 1, 2, 3, 4, 5, 6 and 7.
- A fourth data set (Set D), which included all responses except those that explicitly stated that they had experienced difficulties, but incorporating cases where individuals had ranked several options as 1 etc. into the weighting.

The rankings in each set as a whole appear to be similar.

For each of these sets, those respondents with dementia, their carers, and those who work with them, were separated out to examine differences. Individuals with dementia, their carers, and individuals who worked with them, placed greater importance on the provision of specialist community support and less importance on the improved professional awareness and understanding of dementia than the wider group.

**People with dementia, their carers, and professionals who work with people with dementia**

|   | <b>Set A</b>                          | <b>Set B</b>                          | <b>Set C</b>                  | <b>Set D</b>                  |
|---|---------------------------------------|---------------------------------------|-------------------------------|-------------------------------|
| An increase in specialist community personal care and support services for people with dementia   | <i>N/a only one response</i>          | <i>N/a only two response</i>          | 1st                           | 1st                           |
| Improved early diagnosis and intervention   |                                       |                                       | 2nd                           | 2nd                           |
| Good quality information and advice for those with diagnosed dementia and their carers  |                                       |                                       | 3rd                           | 3rd                           |
| An increase in specialist dementia support in care homes or supported housing   |                                       |                                       | 4th                           | 4th                           |
| Improved professional awareness and understanding of dementia   |                                       |                                       | 5th                           | 5th                           |
| Further development of support and learning networks so that people with dementia and their carers can talk to and learn from other people who have experienced the same issues |                                       |                                       | 6th                           | 6th                           |
| <i>Total respondents</i>  |                                       |                                       | <i>21</i>                     | <i>22</i>                     |
| <i>Source</i>   | <i>Paper &amp; text response only</i> | <i>Paper &amp; text response only</i> | <i>Incl. online responses</i> | <i>Incl. online responses</i> |

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**19. Is there a priority for people with dementia and their carers that we have not covered above?**

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Other priorities identified by respondents included:

- Dementia specialist nurses and key workers.
- An increase in specialist care facilities for people with dementia.
- Regular high-quality respite care including a night service.
- Needs assessments for the carers of people with dementia.

- More stimulation for people with dementia in long term care wards (including the Lighthouse Wards) and care homes.
- Improved public education and awareness of dementia.
- A legal requirement for all people working in care to have ongoing dementia training.
- Introducing an EMI certificate for nursing care.
- Increased user involvement and voice for people with dementia.
- Addressing stigma in the community.
- A GP register of patients.
- A quality outcomes framework for monitoring dementia services.
- Ongoing training and dementia champions.
- Risk assessments for carers of people with dementia.
- A social media page for carers where people can ask questions and seek support.
- That there was a need to distinguish between dementia care and caring for individuals with challenging behaviour.

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## **20. Do you feel that there is an unmet demand for adult mental health services (other than dementia and memory loss) for people with enduring support needs, if so please provide a brief explanation?**

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There was a significant level of general concern regarding the availability of mental health services and the level of unmet need in the community. Respondents commented on:

- The popularity of STAR (support time and recovery) workers and suggested that this service could usefully be expanded.
- A lack of local training opportunities for mental health staff.
- Long waiting times following referral being of serious concern.
- Out of hours support was felt to be lacking.
- Provision for people with alcohol related disorders was a concern since residential facilities often did not admit people who had been drinking – that there was a need for a ‘wet house’.
- Accommodation provided to mental health service users being unsuitable.



- A need for more preventative community services within the mental health service to help to prevent escalation to crisis and hospital admissions.
- Significant concerns about problems with the stigma attached to mental health conditions in the community.
- Individuals with both autism and a mental health condition receiving appropriate support.
- The difference between the level of support someone received in Albecq Ward compared to the level they received when they were discharged.
- The addiction service, and whether it could include mentoring from people who had faced addiction themselves.
- Staff turnover within the service.
- An Alderney respondent felt that there was a lack of services and significant demand in Alderney.

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## **21. How important do you think the following is to carers? Please rate from 1 to 7 with 1 being the highest of importance:**

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As with question 18, whilst 193 respondents submitted responses to the question, 12 respondents reported technical problems with surveymonkey and experienced difficulty assigning the rankings that they wished to assign. It is possible that others submitting via surveymonkey had similar problems but did not tell us, in which case there is some uncertainty over whether the surveymonkey responses are accurate representations of people's views.

Fewer respondents ranked all options as '1' compared with question 18, though some did do this. Twelve respondents wished to assign weightings rather than ranks with several options being assigned the same number (e.g. 1,2,1,3,3,1).

Consequently, in order to give consideration to the reliability of data and the varied approaches to responding four data sets have been compared and analysed:

- One data set (set A), which included only written responses that have not encountered technical difficulties, or where the ranking order was stated in free text in surveymonkey. Only responses which were ranked 1, 2, 3, 4, 5 and 6 were taken as valid. This amounted to 16 responses.

- A second data set (set B), which included only written responses that have not encountered technical difficulties, or where the ranking order was stated in the free text in surveymonkey. This incorporated cases where individuals had ranked several options as 1 etc. into the weighting. This incorporated a further 7 responses bringing the total to 23.
- A third data set (set C), which included all responses except those that explicitly stated that they had experienced difficulties (with any of the ranking questions) but only including responses which were ranked 1, 2, 3, 4, 5, and 6.
- A fourth data set (set D), which included all responses except those that explicitly stated that they had experienced difficulties (with any of the ranking questions) but incorporating cases where individuals had ranked several options as 1 etc. into the weighting.

**Overall weighted ranking for data sets**

|  | <b>Set A</b>                          | <b>Set B</b>                          | <b>Set C</b>                  | <b>Set D</b>                  |
|--|---------------------------------------|---------------------------------------|-------------------------------|-------------------------------|
| Respite care   | 1st                                   | 1st                                   | 1st                           | 1st                           |
| A carer's assessment which would identify the support carers need to continue caring   | 2nd                                   | 2nd                                   | 2nd                           | 2nd                           |
| More general support   | 5th                                   | 3rd                                   | 3rd                           | 3 <sup>rd</sup>               |
| Training and advice about the care and support needs of the person they care for       | 3rd                                   | 5th                                   | 4th                           | 4 <sup>th</sup>               |
| Information and advice for carers on services and other forms of help available        | 4th                                   | 4th                                   | 5th                           | 5 <sup>th</sup>               |
| Support when caring role substantially changes or ends                                 | 6th                                   | 6th                                   | 6th                           | 6 <sup>th</sup>               |
| Changes to Carer's Allowance (if so please specify what changes in the question below) | 7th                                   | 7th                                   | 7th                           | 7 <sup>th</sup>               |
| <i>Total respondents</i>   | <i>17</i>                             | <i>28</i>                             | <i>171</i>                    | <i>182</i>                    |
| <i>Source</i>  | <i>Paper &amp; text response only</i> | <i>Paper &amp; text response only</i> | <i>Incl. online responses</i> | <i>Incl. online responses</i> |

**Responses from carers only**

|  | <b>Set A</b>     | <b>Set B</b>     | <b>Set C</b>     | <b>Set D</b>     |
|--|------------------|------------------|------------------|------------------|
| A carer's assessment which would identify the support carers need to continue caring   | Only 2 responses | Only 4 responses | 1st              | 1st              |
| Training and advice about the care and support needs of the person they care for       |                  |                  | 2nd              | 3rd              |
| Respite care   |                  |                  | 3rd              | 2nd              |
| More general support   |                  |                  | 4th              | 4th/5th          |
| Information and advice for carers on services and other forms of help available        |                  |                  | 5th              | 4th/5th          |
| Support when caring role substantially changes or ends                                 |                  |                  | 6th              | 6th              |
| Changes to Carer's Allowance (if so please specify what changes in the question below) |                  |                  | 7th              | 7th              |
| <i>Total respondents</i>   |                  |                  | <i>28</i>        | <i>30</i>        |
| <i>Reliability</i>   | <i>Reliable</i>  | <i>Reliable</i>  | <i>Uncertain</i> | <i>Uncertain</i> |

Comments on this question included:

- That physically having a person present to help for even a very short amount of time a week made more of a difference to families than other interventions such as training.
- Lack of clarity about what 'more general support' meant.
- The financial value of informal care and the fact that carer breakdown could often cause admission of the cared-for individual to relatively expensive residential care.

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## 22. Is there a priority for carers that we have not covered above?

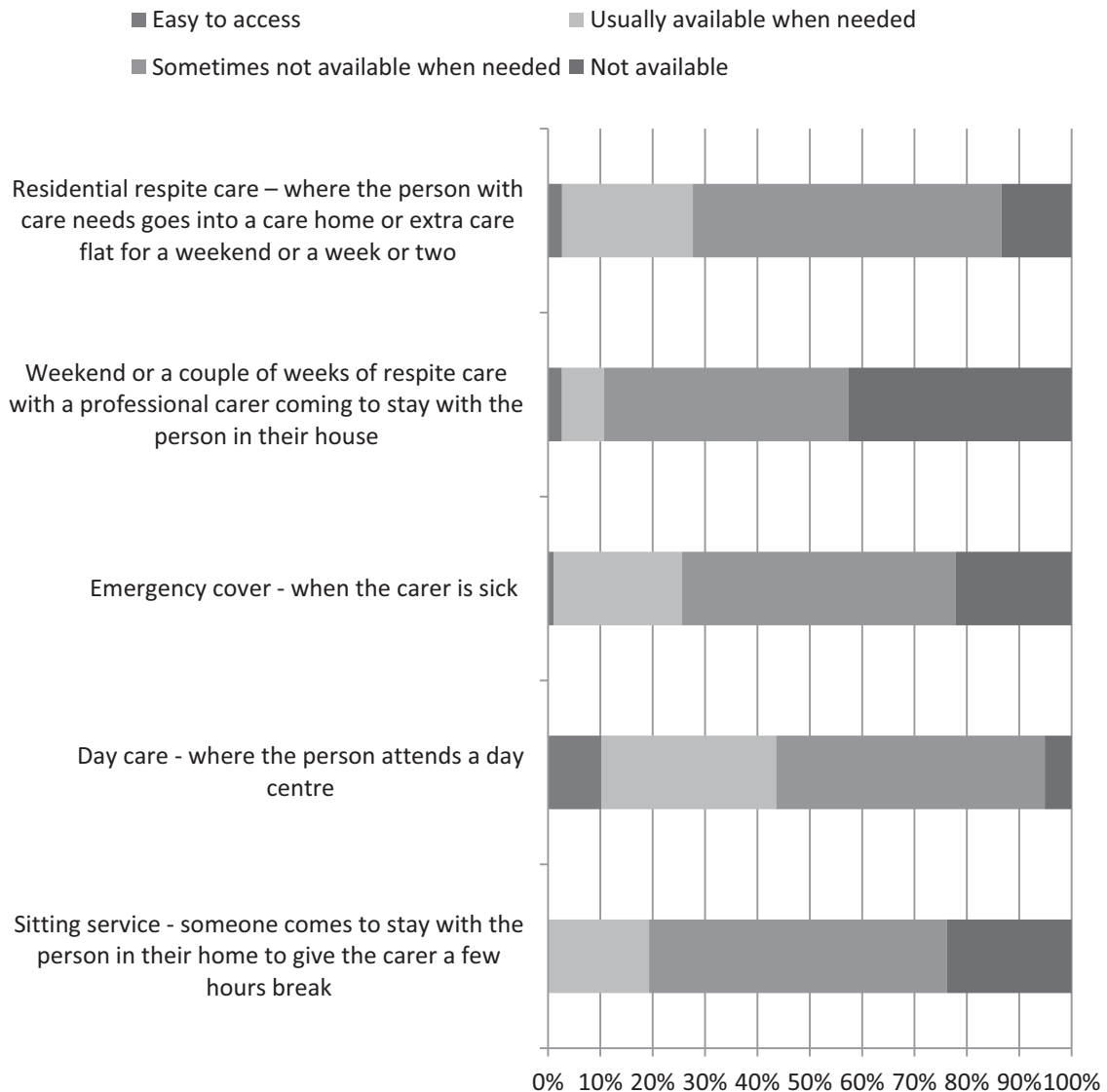
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Suggestions of priorities from respondents included:

- Peer support from other carers.
- Reliable respite care that can be pre-booked.
- Risk assessments for carers supporting people with cognitive disorders.
- More general training for carers, including emotional wellbeing and manual handling.
- Counselling for carers.
- Having a contact to check on carers and who they can call when they need support.
- Help filling in forms and legal documents.
- Targeted help for young carers.
- Assessments and offers of help should be undertaken as a matter of course, rather than waiting for an individual to ask for an assessment or help.
- Financial support for those who cannot access Carer's Allowance.
- The need for day centres.
- Support for carers to maintain their independence.
- Personal budgets for carers.

## 23. To what extent do you think the following types of respite care are easy to access in Guernsey?

A significant majority of respondents felt that all forms of respite care were sometimes unavailable or not available when needed.



|   | Easy to<br>access | Usually<br>available<br>when<br>needed | Sometimes<br>not<br>available<br>when<br>needed | Not<br>available | Total |
|---|-------------------|--|---|------------------|-------|
| Sitting service - someone comes to stay with the person in their home to give the carer a few hours break                           | 0%<br>0           | 19%<br>17                              | 57%<br>50                                       | 24%<br>21        | 88    |
| Day care - where the person attends a day centre  | 10%<br>12         | 33%<br>39                              | 51%<br>60                                       | 5%<br>6          | 117   |
| Emergency cover - when the carer is sick  | 1%<br>1           | 24%<br>21                              | 52%<br>45                                       | 22%<br>19        | 86    |
| Weekend or a couple of weeks of respite care with a professional carer coming to stay with the person in their house                | 3%<br>2           | 8%<br>6                                | 47%<br>35                                       | 42%<br>32        | 75    |
| Residential respite care – where the person with care needs goes into a care home or extra care flat for a weekend or a week or two | 3%<br>3           | 25%<br>28                              | 59%<br>66                                       | 13%<br>15        | 112   |

**Comments related to this question included:**

- “often awaiting a crisis at home prior to any respite”.
- Respite care was difficult to book and the lack of availability of respite care for planned breaks meant that carers had to resort to expensive private services; for example: “we received confirmation... two days prior to our vacation... Second time... we could not obtain respite so engaged... privately”.
- Concerns about respite being used as a way into long term care in residential homes or as palliative care.
- That there was demand for respite care provided in a person’s own home.
- The range of services available needed to increase.
- Planned respite provision was useful for the carer to enable them to help the individual they were caring for plan for and adjust to the idea, or even familiarise themselves with the environment, before the carer left, rather than waiting for a last minute decision.

- Sometimes individuals living alone without a carer may need temporary assistance and this should be available to them in a similar way.
- There was a concern about the lack of availability of respite services in Alderney.

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## **24. To what extent do you think that existing respite care services cater to the needs of the following groups**

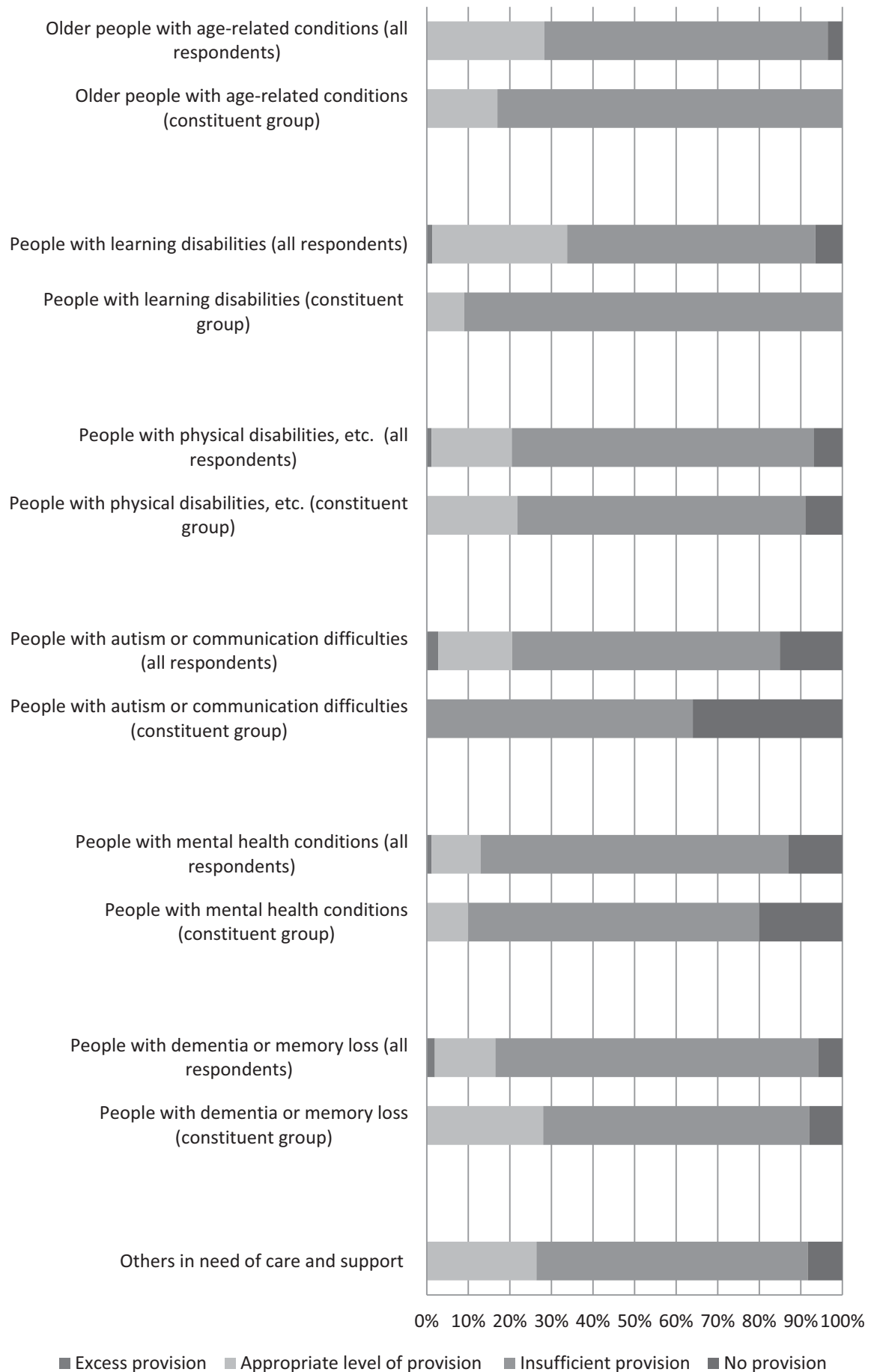
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More than half of respondents felt that there was insufficient provision for respite care services for all of the groups.

More than half of Alderney respondents felt that there was insufficient provision for respite care for most of the groups.

The graph compares all respondents with constituent groups. 'Constituent groups' include respondents who identified themselves as individuals with a specific condition, their carers, and professionals who worked with people with this condition. In some cases the 'constituent group' is a very small sample size (see table).





|   | Excess provision | Appropriate level of provision | Insufficient provision | No provision | Total |
|---|------------------|--------------------------------|------------------------|--------------|-------|
| Older people with age-related conditions  | 0%<br>0          | 28%<br>32                      | 68%<br>77              | 4%<br>4      | 113   |
| <i>Responses of people with age-related conditions, their carers, and those who work with them</i>  | 0%<br>0          | 17%<br>3                       | 83%<br>15              | 0%<br>0      | 18    |
| People with learning disabilities   | 1%<br>1          | 32%<br>25                      | 60%<br>46              | 6%<br>5      | 77    |
| <i>Responses of people with learning disabilities, their carers, and those who work with them</i>   | 0%<br>0          | 9%<br>1                        | 91%<br>10              | 0%<br>0      | 11    |
| People with physical disabilities, chronic illness, brain injury, sensory impairment or neurological conditions   | 1%<br>1          | 19%<br>17                      | 73%<br>64              | 7%<br>6      | 88    |
| <i>Responses of people with physical disabilities, chronic illness, brain injury, sensory impairment or neurological conditions, their carers, and those who work with them</i> | 0%<br>0          | 22%<br>5                       | 70%<br>16              | 9%<br>2      | 23    |
| People with autism or communication difficulties  | 3%<br>2          | 18%<br>13                      | 64%<br>47              | 15%<br>11    | 73    |
| <i>Responses of people with autism or communication difficulties, their carers, and those who work with them</i>  | 0%<br>0          | 0%<br>0                        | 64%<br>7               | 36%<br>4     | 11    |
| People with mental health conditions  | 1%<br>1          | 12%<br>10                      | 74%<br>63              | 13%<br>11    | 85    |
| <i>Responses of people with mental health conditions, their carers, and those who work with them</i>  | 0%<br>0          | 10%<br>1                       | 70%<br>7               | 20%<br>2     | 10    |

|  | Excess provision | Appropriate level of provision | Insufficient provision | No provision | Total |
|--|------------------|--------------------------------|------------------------|--------------|-------|
| People with dementia or memory loss  | 2%<br>2          | 15%<br>15                      | 78%<br>80              | 6%<br>6      | 103   |
| <i>Responses of people with dementia or memory loss , their carers, and those who work with them</i> | 0%<br>0          | 28%<br>7                       | 64%<br>16              | 8%<br>2      | 25    |
| Others in need of care and support   | 0%<br>0          | 26%<br>19                      | 65%<br>47              | 8%<br>6      | 72    |

Respite care is provided through the learning disability service, however, respondents were concerned that this is not available, and there is no alternative provision, for individuals who have autism but do not have a learning disability.

Some respondents felt that the respite available for individuals with complex needs in the Lighthouse Wards was not appropriate due to its association with individuals with dementia and challenging behaviour.

Some respondents felt that the loss of the community home at the Croft was detrimental for adults with learning disabilities since this allowed people to socialise with others that they knew, and that individual respite services were not an adequate substitute.

It was noted that the only respite available for people with mental health conditions was at the Albecq Ward and it was felt that this was not ideal.

There was concern that residential and nursing homes were being used to provide respite to younger people with care needs and that this was inappropriate.

There were concerns that respite care was limited in availability for people with physical .

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## 25. Do you have any further comments to make in respect of respite care or services?

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It was highlighted that respite care for young people was not about giving their parents 'a break', but could be used to allow the young person and their parents to develop their own friendships/lives/interests as would be normal for a teenager in other circumstances. This was an equality and inclusion issue: "I would rather the services be called 'allow me a life' than making me feel that the service on offer infers that I need a break all the time."

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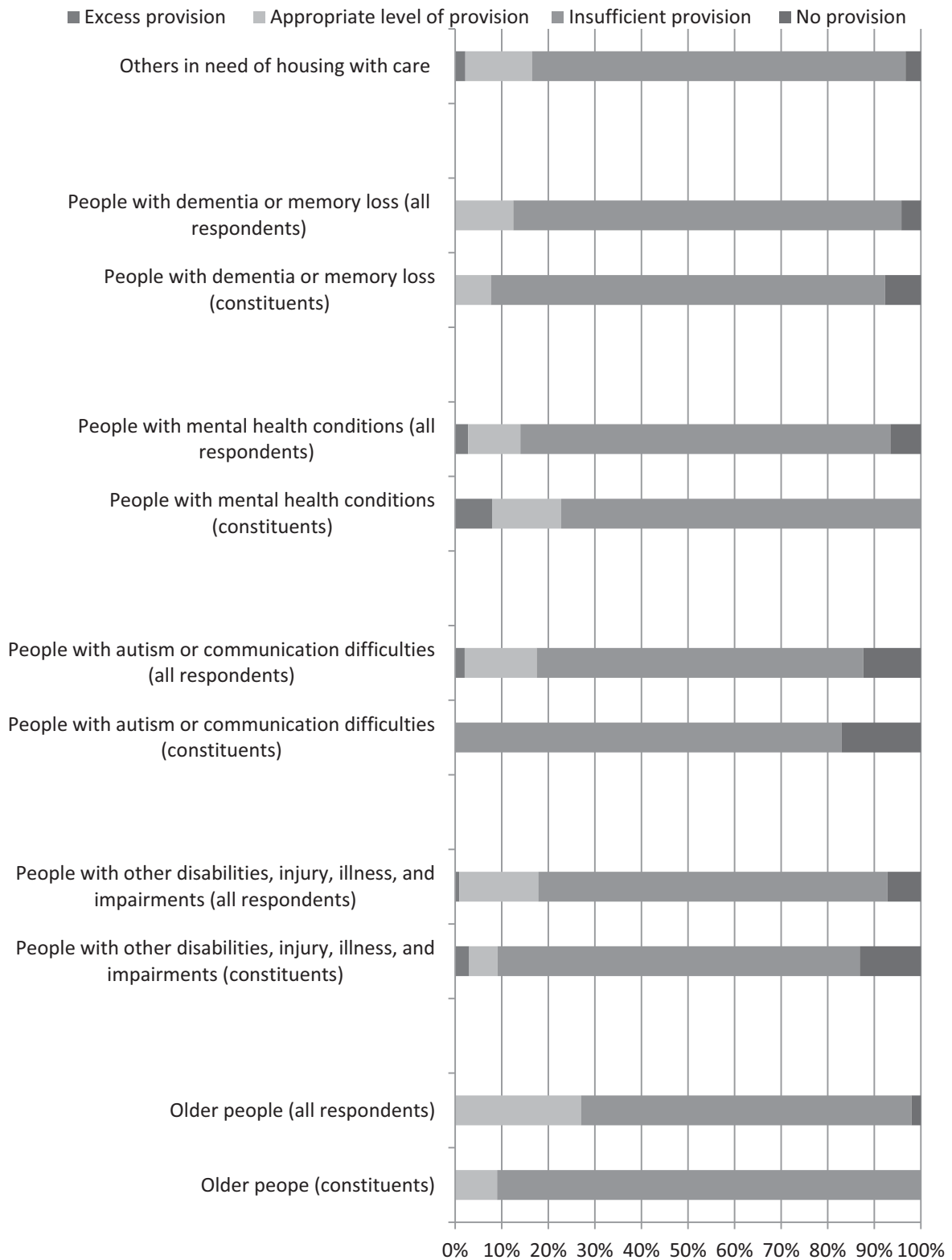
## 26. To what extent do you think that there is an appropriate quality and range of housing with care for the following groups of people?

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*"Housing with care" refers to different kinds of housing where there is some on-site staff support. This incorporates supported housing like extra-care flats, where people have their own apartments but there are staff providing care or support to the apartment block, or residential care homes where residents live in their own room but share communal areas with staff supporting all residents.*

Over 70% of respondents felt that there was insufficient provision of appropriate quality and range of housing with care for all groups.

More than 60% of Alderney respondents felt that there was no provision of appropriate quality and range of housing with care for people with learning disabilities, people with autism or communication difficulties, and people with mental health conditions.



|  | Excess provision | Appropriate level of provision | Insufficient provision | No provision | Total |
|--|------------------|--------------------------------|------------------------|--------------|-------|
| Older people (all respondents)   | 0%<br>0          | 27%<br>40                      | 71%<br>105             | 2%<br>3      | 148   |
| <i>Respondents identifying as individuals with age related conditions, their carers, and professionals who work with them</i>      | 0%<br>0          | 9%<br>2                        | 91%<br>21              | 0%<br>0      | 23    |
| People with learning disabilities, chronic illness, brain injury, neurological conditions or sensory impairments (all respondents) | 1%<br>1          | 17%<br>19                      | 75%<br>84              | 7%<br>8      | 112   |
| <i>Respondents identifying as individuals belonging to this group, their carers, and professionals who work with them</i>          | 3%<br>1          | 6%<br>2                        | 77%<br>24              | 13%<br>4     | 31    |
| People with autism or communication difficulties   | 2%<br>2          | 15%<br>15                      | 70%<br>68              | 12%<br>12    | 97    |
| <i>Respondents identifying as individuals belonging to this group, their carers, and professionals who work with them</i>          | 0%<br>0          | 0%<br>0                        | 83%<br>10              | 17%<br>2     | 12    |
| People with mental health conditions   | 3%<br>3          | 11%<br>12                      | 79%<br>85              | 7%<br>7      | 107   |
| <i>Respondents identifying as individuals belonging to this group, their carers, and professionals who work with them</i>          | 8%<br>1          | 15%<br>2                       | 78%<br>10              | 0%<br>0      | 13    |
| People with dementia or memory loss  | 0%<br>0          | 13%<br>17                      | 83%<br>121             | 4%<br>6      | 144   |
| <i>Respondents identifying as individuals belonging to this group, their carers, and professionals who work with them</i>          | 0%<br>0          | 8%<br>2                        | 85%<br>22              | 8%<br>2      | 26    |
| Others in need of housing with care  | 2%<br>2          | 14%<br>13                      | 80%<br>73              | 3%<br>3      | 91    |

**Comments on this question included:**

- Concerns that there was no purpose built supported housing for people with autism.
- The lack of specific support for people with physical impairments, chronic illness, brain injuries, sensory impairments and neurological conditions.

- The limited availability of sheltered housing as a level of support lower than extra-care.
- The difficulties of finding suitable housing with care for someone with both learning disabilities and physical impairments.
- The lack of specialist dementia care provision.
- Some members of the public compared the relative merits of extra-care housing and residential care homes, preferring residential care homes. Others felt that extra-care housing was key.
- There were concerns that lack of provision was causing 'bed blocking' in the hospital.
- Some respondents felt there was a need to build more care homes to meet the current demand.
- There was a comment raising concerns about the quality of accommodation offered to mental health service users.
- There were concerns about the restricted options available to young people with disabilities to be able to choose where to live or who to live with.
- Some respondents felt that there were disparities between the listed groups of conditions, with some groups receiving significantly more public sector support than others.
- Some felt that housing with care options could provide better day-to-day choice for individuals than community services.
- The limited range of housing with care available on Alderney.

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## **27. Do you have any comments on the range of services? Do you think there are any other significant gaps in services which are not identified above?**

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There were concerns raised about the availability of 'practical aids or adaptations' including telecare options.

It was felt that services should have a "much stronger emphasis on prevention and re-enablement".

It was felt that there should be more property available on Guernsey to allow people to down-size.

There were some concerns about transport availability.

There were concerns about the availability of adult education.

It was felt that younger people, particularly those who experienced sudden disability, often wanted to live independently and this was not always possible within existing services.

There were concerns that some services rely on a single staff member and there was no cover for annual leave etc.



## Changing the way we think about care, disability and ageing

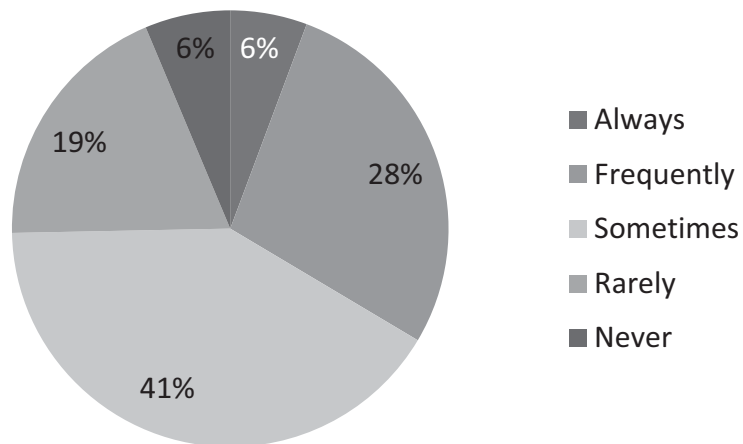
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### 28. People make assumptions about what others want or are interested in based on their age. How frequently do you find these assumptions make it more difficult for you to do what you want?

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The majority of respondents (69%) felt that they sometimes or frequently find the assumptions made by others about what they want or are interested in based on their age made it more difficult to do what they wanted.

Half of Alderney respondents rarely felt that the assumptions made by others about what others want or are interested in based on their age made it more difficult for them to do what they wanted to do.



| Answer choices | Responses                |                        |
|----------------|--------------------------|------------------------|
|                | Percentage               | Actual no. respondents |
| Frequently     | 28%                      | 44                     |
| Sometimes      | 41%                      | 65                     |
| Rarely         | 19%                      | 30                     |
| Never          | 6%                       | 10                     |
| Always         | 6%                       | 9                      |
|                | <b>Total respondents</b> | 158                    |

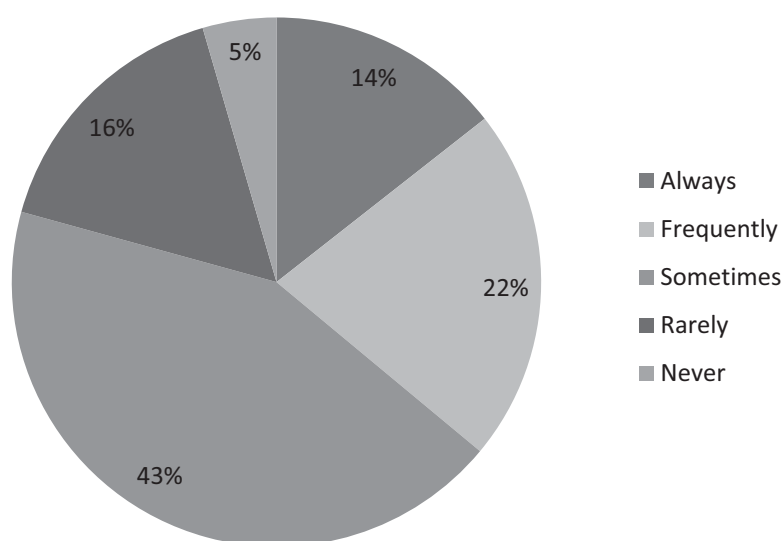
It was suggested that people's choices were often restricted; and whilst this had something to do with attitudes, it also had to do with the limited choices available and lack of awareness about existing activities. It was suggested that there was a need to find out what there was demand for and consider providing activities where there were none available.

There was support for a wider 'ageing well' agenda, including promotion of positive attitudes towards ageing.

Some older respondents felt that they had been patronised by care staff.

## 29. How often do you feel that your views are included in decisions made about your care and support?

A majority of respondents (64%) felt that their views were never, rarely or sometimes included in decisions made about their care and support.



| Answer choices | Responses                |                        |
|----------------|--------------------------|------------------------|
|                | Percentage               | Actual no. respondents |
| Always         | 14%                      | 16                     |
| Frequently     | 22%                      | 24                     |
| Sometimes      | 43%                      | 48                     |
| Rarely         | 16%                      | 18                     |
| Never          | 5%                       | 5                      |
|                | <b>Total respondents</b> | 111                    |

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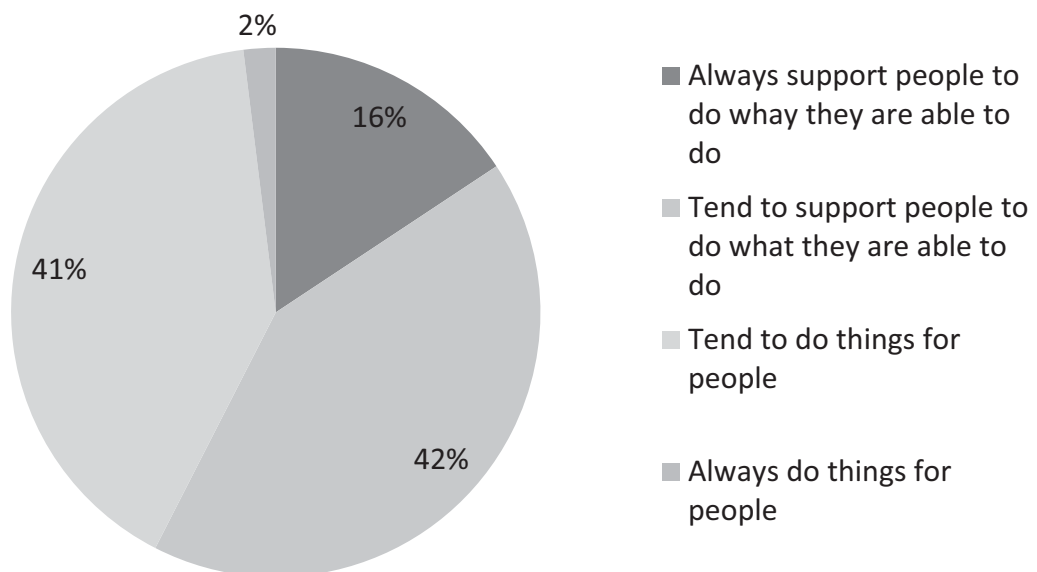
**30. How frequently, from your experience, do care staff aim to enable the people that they work with to do as much as they are able to (rather than doing things for them)?**

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The majority of respondents (58%) felt that care staff always or tended to support people to do what they are able to do rather than doing things for people.

Over half of Alderney respondents (58%) felt that care staff tended to support people to do what they are able to do.

However, there remained a significant number of people who felt that care staff did things for them rather than supporting them to do what they could.



| Answer Choices  | Responses  |                        |
|---|------------|------------------------|
|   | Percentage | Actual no. respondents |
| Always support people to do what they are able to do  | 16%        | 24                     |
| Tend to support people to do what they are able to do | 42%        | 64                     |
| Tend to do things for people                          | 41%        | 62                     |
| Always do things for people                           | 2%         | 3                      |
| <b>Total respondents</b>                              |            | 153                    |

Some respondents suggested that whilst care and support staff recognise the importance of enabling the people who they support, this was not always practical or it was felt that there were time constraints which prevented this.

Some respondents felt that the codes of professional practice meant that all staff would support people to do what they were able.

The need for training to support staff to enable the people they worked with was highlighted.

There was also some concern about the psychological aspect of support– that care staff could be overly positive and not allow people to talk through their anxieties.

Particular concerns were raised about support for people with dementia.

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**31. Do you have experience of someone with care or support needs having their aspirations limited because of the attitudes or expectations of the people around them? Do you have suggestions about what could be done to change attitudes or address social isolation?**

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**Prejudice and attitudes**

- There was some criticism that not all members of the States personally promoted disability inclusion.
- There were concerns about the stigma surrounding mental health conditions.
- It was felt there was a need to raise awareness of, and address attitudes towards, dementia within the community.
- There were concerns about attitudes towards disabled people, and reportedly assumptions from some members of the public that those with a visible physical disability also had a cognitive impairment or learning disability.
- There were concerns that in some cases staff were speaking to carers without asking individuals their own views about their care or decisions that might be made about them.
- Some respondents emphasised the need for the States and society to champion equal choice and opportunities to 'have a life', work and live independently for disabled people, and that services should support this.
- One respondent commented that the level of expectation and aspiration for people with autism was too low, and that this could prevent people from reaching their potential by affecting self-esteem and the way in which problems are managed.
- Other respondents were concerned about the level of expectation for the lives of young people in special needs education.

**Social inclusion and loneliness**

The following themes emerged:

- It was emphasised that care should be arranged with an awareness of the importance and need for continuity within existing personal relationships to ensure that care and support decisions did not lead to social isolation. This

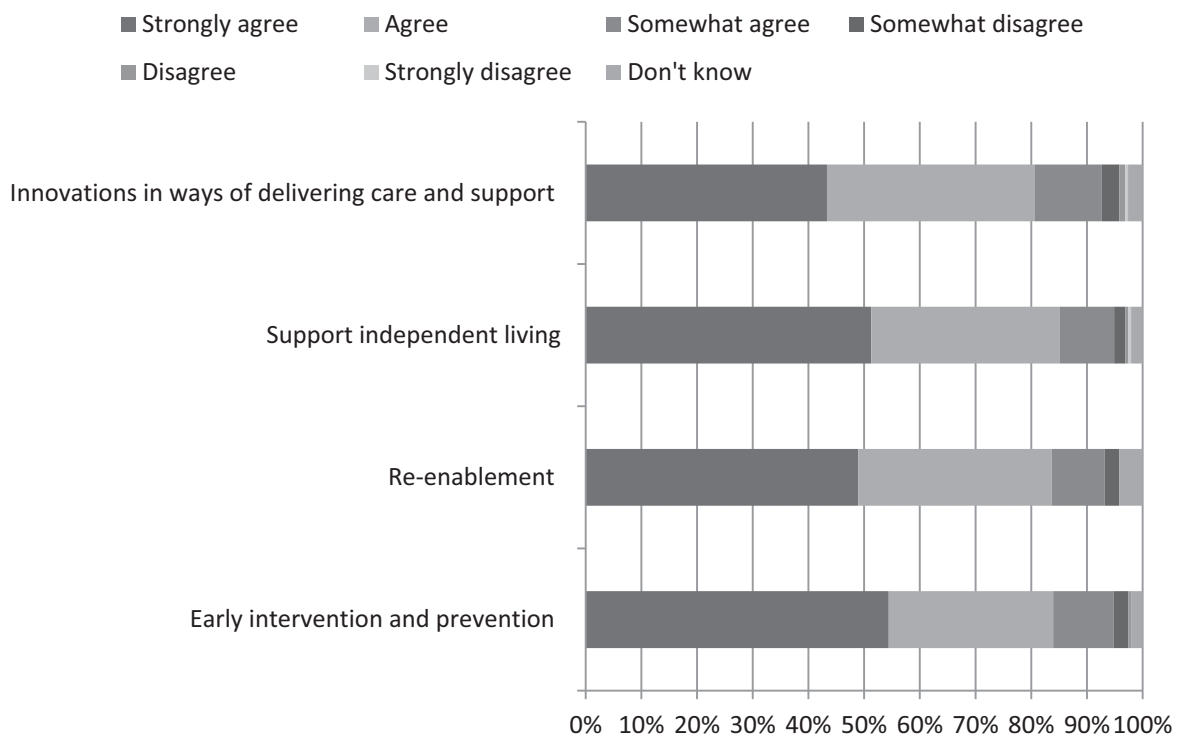
included consideration about arrangements for partners or couples where one developed a care need and they did not wish to be separated.

- The need to support informal/family carers and ensure that they did not become isolated because of their caring role was highlighted.
- Some respondents felt that the third sector could play a significant role in addressing social isolation. There was significant interest in developing a broader befriending scheme.
- It was felt that activities in, and outings from, care homes should reflect the range of interests of the individuals living there and allow for connection with the wider community.
- Questions were raised over whether States-run day centres, currently largely focused on those living in the community, should be more open to the attendance of care home residents.
- The importance of transportation in preventing social isolation was highlighted. One aspect of this was the transport links and location of supported housing like the new extra-care housing, which some felt was not close to community facilities.
- There were also concerns about the possibility that activities for older people focused on games or bingo and did not suit quieter older people; there was a need to support people to pursue their interests.
- The risk of social isolation facing young people transitioning into adult services was raised.
- Parish-based day-centres for older people were suggested.
- An issue with lack of activity or support for young adults with disabilities was raised as this was felt to be detrimental to the social inclusion of the young adults and their parents.
- There were concerns that if independent living and telecare were pursued that this would lead to loneliness.
- The advantage of residential care, extra-care and supported housing in helping to prevent social isolation was emphasised.
- The importance of ensuring that people had opportunities to be digitally included and able to use mobile phones and the internet was highlighted.

## How do we pay?

### 32. To what extent do you agree that pursuing these ways of reducing cost merits some further investigation?

The majority of respondents agreed or strongly agreed that all of the proposed ways of reducing cost merited some further investigation.





|   | <b>Strongly agree</b> | <b>Agree</b> | <b>Somewhat agree</b> | <b>Somewhat disagree</b> | <b>Disagree</b> | <b>Strongly disagree</b> | <b>Don't know</b> | <b>Total</b> |
|---|-----------------------|--------------|-----------------------|--------------------------|-----------------|--------------------------|-------------------|--------------|
| <b>Early intervention and prevention</b>                  | 54%<br>105            | 30%<br>57    | 11%<br>21             | 3%<br>5                  | 1%<br>1         | 0%<br>0                  | 2%<br>4           | 193          |
| <b>Re-enablement</b>                                      | 49%<br>93             | 35%<br>66    | 9%<br>18              | 3%<br>5                  | 0%<br>0         | 0%<br>0                  | 4%<br>8           | 190          |
| <b>Supporting independent living</b>                      | 51%<br>100            | 34%<br>66    | 10%<br>19             | 2%<br>4                  | 1%<br>1         | 1%<br>1                  | 2%<br>4           | 195          |
| <b>Innovations in ways of delivering care and support</b> | 43%<br>83             | 37%<br>72    | 12%<br>24             | 3%<br>6                  | 1%<br>2         | 1%<br>1                  | 3%<br>5           | 193          |

There was support for the idea that proper provision of aids, adaptations and telecare may lead to cost savings in the long-term.

It was felt that transition training flats might help some people with support needs to move from living with their parents to independent living.

There was a suggestion that any introduction of technological innovation be accompanied by training and support for cultural change.

Many respondents felt that the possibility of reducing demand through preventative measures, health promotion and suitable housing arrangements was underemphasised in the consultation document.

Electronic health records was one area of technological advance which was felt might be helpfully pursued.

There were concerns about the lack of physiotherapy and occupational therapy available.

There were some concerns that health promotion initiatives were 'wasting money'.

There were particular concerns about rehabilitation after a stroke.

It was felt that early intervention and prevention could be usefully pursued in the mental health service.

It was felt that adaptations to housing needed to be prioritised.

There were concerns that independent living and telecare would lead to loneliness.

It was felt that independent living was resource intensive, not suitable for everyone, and may not lead to optimum wellbeing for everyone.

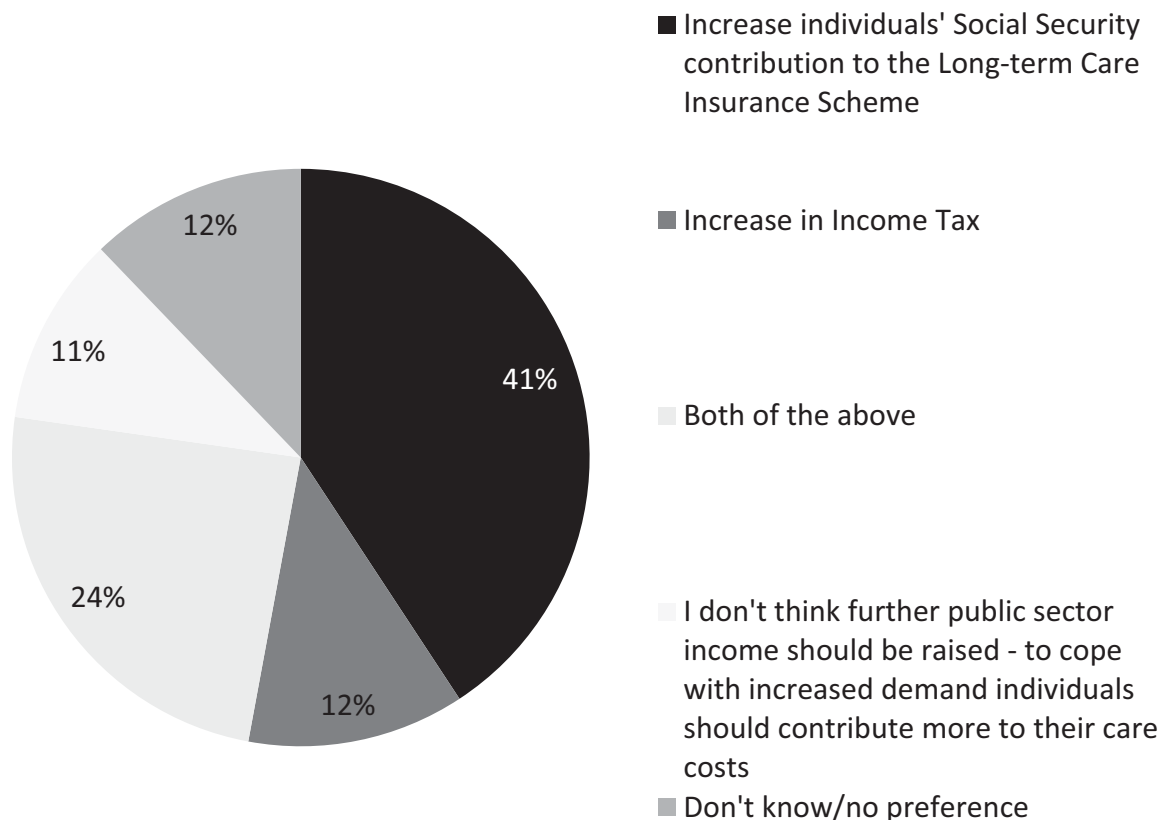
Some respondents felt that there was a need for intermediate care (i.e. residential care as a temporary support to help with re-enablement and rehabilitation after a hospital stay, or to prevent hospitalisation – where the individual is supported to become gradually more independent before returning to their own home).

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**33. Additional public funds may be needed to make the long-term care system sustainable, how should these be raised? Please tick the most relevant statement.**

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Just under half of respondents (40%) felt that funds should be raised by increasing individuals' Social Security contributions to the Long-term Care Insurance Scheme. All Alderney respondents felt that the funds should be raised through both increasing individuals' Social Security contributions to the Long-term Care Insurance Scheme and increased Income Tax.



| Answer Choices   | Responses  |                        |
|--|------------|------------------------|
|  | Percentage | Actual no. respondents |
| Increase individuals' Social Security contribution to the Long-term Care Insurance Scheme  | 41%        | 77                     |
| Increase in Income Tax   | 12%        | 23                     |
| Both of the above  | 24%        | 46                     |
| I don't think further public sector income should be raised – to cope with increased demand individuals should contribute more to their care costs | 11%        | 20                     |
| Don't know/no preference   | 12%        | 23                     |
| <b>Total respondents</b>   |            | 189                    |

Of 37 relevant comments received, 27 supported raising Social Security contributions, 5 felt that no further public funding should be raised, and 5 felt that funding should be raised via different kinds of taxation.

Some of those respondents who supported raising Social Security contributions did so with the proviso that the States restructure its existing services to make them more efficient and sustainable.

---

**34. Which of the following would you prefer as methods of increasing an individual's contribution towards their care costs if this were necessary? Please number in priority order from 1 to 3 with number 1 being your first preference.**

---

As with the other questions which involved ranking options, some respondents experienced difficulty with this question.

Whilst 184 respondents submitted responses to the question, most of whom did not report problems with the system, some respondents reported technical problems with the response on surveymonkey and experienced difficulty assigning the rankings that they wished to assign. It is possible that others submitting via surveymonkey had similar problems but did not tell us, in which case there is some uncertainty over whether the surveymonkey responses are accurate representations of people's views.

A number of respondents wished to tick one or two of the options indicating those which they found most acceptable rather than list the available options in order of preference. A couple of respondents felt that none of the options listed were acceptable.

Consequently, in order to give consideration to the reliability of data and the varied approaches to responding, four data sets have been compared and analysed:

- One data set (set A), which included only written responses that have not encountered technical difficulties, or where the ranking order was stated in free text in surveymonkey. Only responses which were ranked 1, 2 and 3 were taken as valid. This amounted to 20 responses.
- A second data set (set B), which included only written responses that did not encounter technical difficulties, or where the ranking order was stated in the free text in surveymonkey. This incorporated cases where individuals had ticked or highlighted one or two options etc. into the weighting. This incorporated a further 10 responses bringing the total to 30.
- A third data set (set C), which included all responses except those that explicitly stated that they had experienced difficulties (with any of the ranking questions), but only including responses which were ranked 1, 2 and 3.

- A fourth data set (set D), which included all responses except those that explicitly stated that they had experienced difficulties (with any of the ranking questions), but incorporating cases where individuals had ranked several options as 1 etc. into the weighting.

**Overall weighted ranking for data sets**

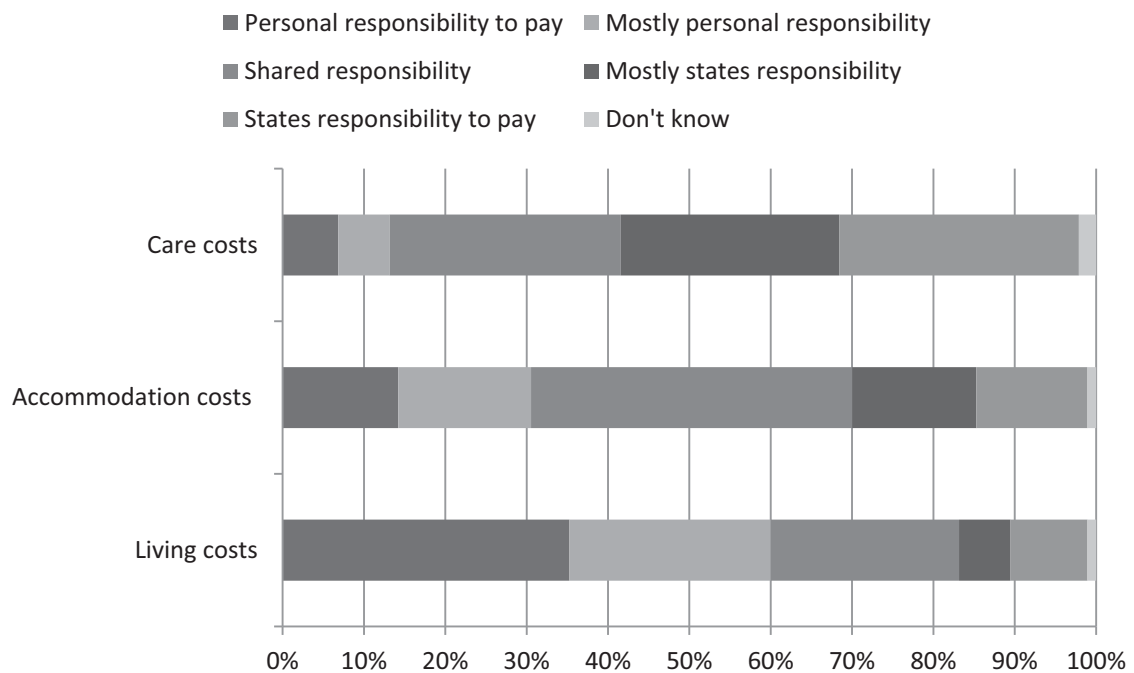
|   | <b>Set A</b>                          | <b>Set B</b>                          | <b>Set C</b>                  | <b>Set D</b>                  |
|---|---------------------------------------|---------------------------------------|-------------------------------|-------------------------------|
| Increase the long-term care co-payment (individuals who can afford to would pay a higher weekly contribution to their care costs)                   | 1 <sup>st</sup>                       | 2 <sup>nd</sup>                       | 1 <sup>st</sup>               | 1 <sup>st</sup>               |
| Means test funding for all care services so people who can afford to are asked to pay (people pay as much towards their care as they can afford to) | 2 <sup>nd</sup>                       | 1 <sup>st</sup>                       | 3 <sup>rd</sup>               | 3 <sup>rd</sup>               |
| Introduce a care cost cap (people who can afford to pay the first £XX,000 towards their care costs, after which the States contributes)             | 3 <sup>rd</sup>                       | 3 <sup>rd</sup>                       | 2 <sup>nd</sup>               | 2 <sup>nd</sup>               |
| <i>Total respondents</i>  | <i>20</i>                             | <i>30</i>                             | <i>167</i>                    | <i>173</i>                    |
| <i>Source</i>   | <i>Paper &amp; text response only</i> | <i>Paper &amp; text response only</i> | <i>Incl. online responses</i> | <i>Incl. online responses</i> |

A few respondents commented in support of increasing the co-payment.

One respondent commented in support of a cost cap mechanism.

### 35. Where people can afford to pay, should the States or the individual bear more of the responsibility?

Whilst the majority of respondents (60%) supported the individual being all or largely responsible for funding their living costs, there was a majority (56%) expectation that the States should cover all or most care costs. There was an almost even split when it came to accommodation costs.



|                        | Personal<br>responsibility to<br>pay | Mostly personal<br>responsibility | Shared<br>responsibility | Mostly States<br>responsibility | States<br>responsibility | Don't Know | Total respondents |
|------------------------|--------------------------------------|-----------------------------------|--------------------------|---------------------------------|--------------------------|------------|-------------------|
| Living costs           | 35%<br>67                            | 25%<br>47                         | 23%<br>44                | 6%<br>12                        | 9%<br>18                 | 1%<br>2    | 190               |
| Accommodation<br>costs | 14%<br>27                            | 16%<br>31                         | 39%<br>75                | 15%<br>29                       | 14%<br>26                | 1%<br>2    | 190               |
| Care costs             | 7%<br>13                             | 6%<br>12                          | 28%<br>54                | 27%<br>51                       | 29%<br>56                | 2%<br>4    | 190               |

There were concerns that the administrative cost of separating types of cost would outweigh any financial gains.

Some respondents felt that individuals should be able to opt out of the Long-term Care Insurance Scheme and to be fully personally responsible for their care, living and accommodation costs, and that public funding was unfair on the taxpayer.

Some respondents felt that all assistance should be means tested, regardless of which element (i.e. accommodation, living, care) of the cost was under consideration.

Some respondents felt that those who had paid into the Long-term Care Insurance Scheme should not be expected to pay further costs.

Others felt that the States should cover care costs as a universal right which everyone should have access to.

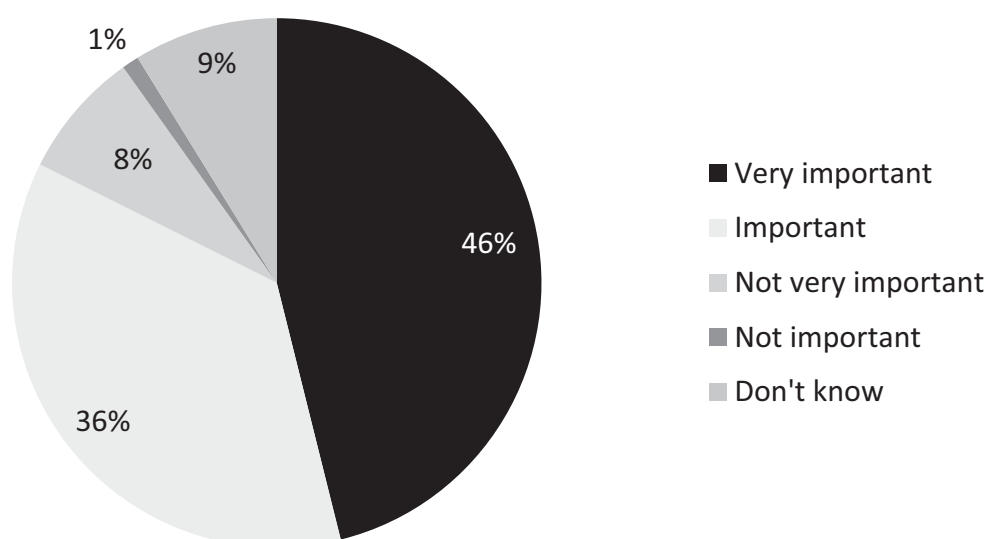
Some respondents highlighted that thought would need to be given as to what was incorporated into 'care' costs if these were separated.

Some respondents felt that beyond care home costs, community care and respite care should also be means-tested.



### 36. How important do you think it is that the long-term care co-payment be linked to the full-rate Old Age Pension so that the co-payment is affordable within the cost of the pension?

The vast majority (82%) felt that it was important or very important that the long-term care co-payment be linked to the full-rate Old Age Pension so that the co-payment was affordable within the cost of the pension.

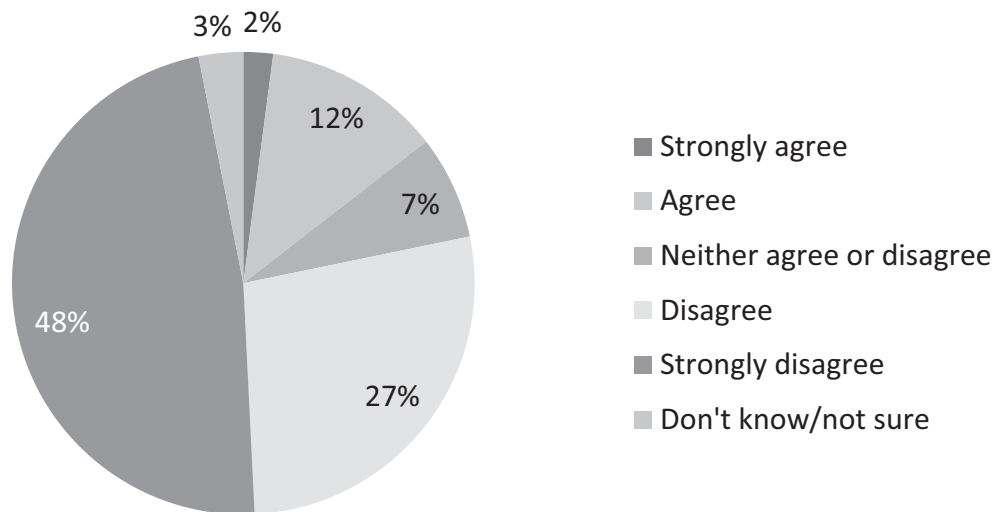


|            | Very important | Important | Not very important | Not important | Don't know | Total respondents |
|------------|----------------|-----------|--------------------|---------------|------------|-------------------|
| Percentage | 46%            | 36%       | 8%                 | 1%            | 9%         |                   |
| Actual     | 89             | 70        | 15                 | 2             | 17         | 193               |

One comment was made to say that the co-payment should be affordable within the Old Age Pension. Another stated that if the pension could not cover accommodation and living costs then the Old Age Pension itself was too low.

### 37. To what extent do you agree or disagree that other family members, as well as spouses and partners, should be financially responsible for a person's long-term care?

A large majority (75%) disagreed or strongly disagreed that other family members, in addition to spouses and partners, should be financially responsible for a person's long term care costs.



| Answer choices            | Response       |                        |
|---------------------------|----------------|------------------------|
|                           | Percentage (%) | Actual no. respondents |
| Strongly agree            | 2%             | 4                      |
| Agree                     | 12%            | 24                     |
| Neither agree or disagree | 7%             | 14                     |
| Disagree                  | 27%            | 53                     |
| Strongly disagree         | 48%            | 92                     |
| Don't know/not sure       | 3%             | 6                      |
| Total respondents         |                | 193                    |

There were concerns about which family members would be responsible.

There were mixed opinions on the financial responsibilities of spouses or partners – some felt that they had more responsibility than other family members; others felt that an individual shouldn't be financially responsible if their partner became ill.

There were concerns about whether family responsibility could be enforced.

Some respondents felt financial responsibility depended on the quality of the relationship particular to the case – and that where family members were estranged it would be inappropriate to ask them to pay.

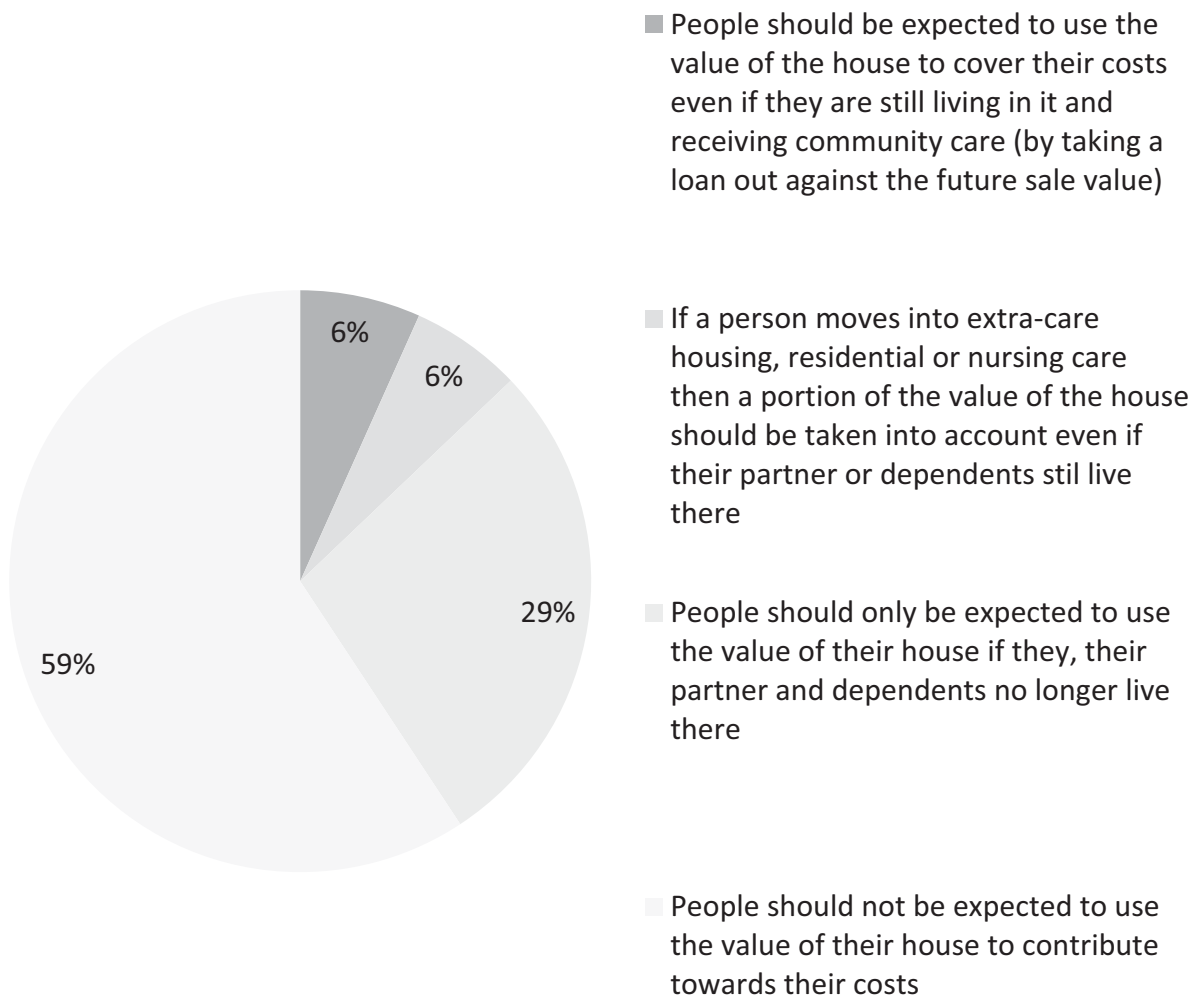
Some respondents felt family responsibility to pay would depend on the financial circumstances of the family member and whether they had disposable income.

There was also a concern that less people would have family members in a position to support them in future, particularly as many would not be resident in Guernsey.

### 38. Do you think the value of houses should be taken into account in means-tests when people apply for financial support from the States to cover care costs?

Over half of respondents (59%) felt that people should not be expected to use the value of their house to contribute towards their costs.

Half of Alderney respondents shared this view and the other half felt that people should only be expected to use the value of their house if they, their partner and dependents no longer lived there.



| Answer Choices   | Responses  |                        |
|--|------------|------------------------|
|  | Percentage | Actual no. respondents |
| People should be expected to use the value of the house to cover their costs even if they are still living in it and receiving community care (by taking a loan out against the future sale value) | 6%         | 12                     |
| If a person moves into extra-care housing, residential or nursing care then a portion of the value of the house should be taken into account even if their partner or dependents still live there  | 6%         | 11                     |
| People should only be expected to use the value of their house if they, their partner or dependents no longer live there   | 29%        | 56                     |
| People should not be expected to use the value of their house to contribute towards their costs  | 59%        | 115                    |
| <b>Total respondents</b>   |            | <b>194</b>             |

Of those respondents that felt that using house sales to pay for care would not be fair:

- Some believed that middle-income earners would be disproportionately affected.
- Some felt that providing funding to those without means, but requiring those who had saved and bought a house to pay, penalised those who had worked hard throughout their lives. Respondents emphasised the amount sacrificed in order to be able to pay off a mortgage.
- There were concerns that wealthy individuals would find ways to protect their assets from being included (e.g. by them being held by a trust).
- Some felt very strongly about wishing to pass on inheritance.
- There were concerns that this would encourage people approaching old age to sell their houses and spend the money as they saw fit before they needed care.
- Some felt that those who needed care would not predict that they will need it nor could they help that they need it, so they should be cared for.

Some respondents felt that the Long-term Care Insurance Scheme should continue to protect against the need to value property assets and there were concerns that to do otherwise would 'move the goal posts'.

There were some concerns about the practicalities of implementation.

Several respondents favoured an increase in Social Security contributions over house sales.

Some respondents set out conditions about how the value of property assets should be treated:

- That a notional rental income should be assessed as income if no dependents lived in the property.
- That houses should only be taken into account if there were no family at all living in the house (regardless of whether they were dependents).
- That it would be discriminatory to distinguish between people with dependents and relatives and those without.
- That if this were to become policy, options for equity release would need to be investigated.

Other respondents felt unequivocally that houses should be incorporated into means testing because:

- It was unfair to require younger people to pay for others' care through tax if they could afford to do so through the value of their property.
- It was the case that houses were included in assessments in the UK and that this seemed reasonable to some respondents.
- They had no expectation of inheritance and did not see it as a right, and felt it more appropriate for the individual to spend their wealth on their own care.
- The value of property was significantly influenced by the time of its purchase and chance, and not only hard-work.

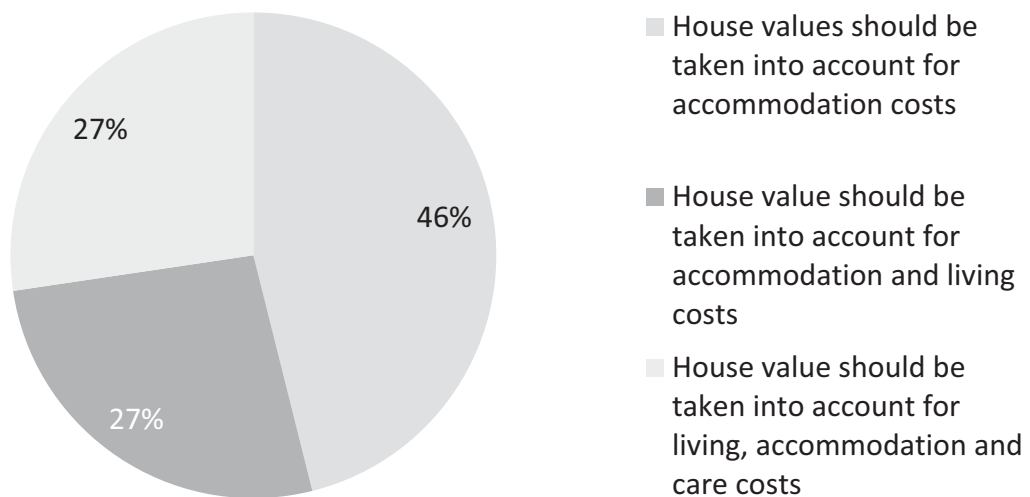
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**39. If houses are taken into account when people apply for means-tested financial support for long-term care, do you think it is significant what part of the cost they are assessed for (tick the most appropriate)?**

---

Just under half of respondents (46%) felt that property value should be taken into account for accommodation costs.

The majority of Alderney residents (60%) felt that property value should be taken into account for accommodation and living costs.



| Answer Choices  | Responses  |                        |
|---|------------|------------------------|
|   | Percentage | Actual no. respondents |
| House value should be taken into account for accommodation costs                  | 46%        | 59                     |
| House value should be taken into account for accommodation and living costs       | 27%        | 34                     |
| House value should be taken into account for living, accommodation and care costs | 27%        | 35                     |
| <b>Total respondents</b>  |            | <b>128</b>             |

There were a few comments noting that respondents didn't find any of these options acceptable as they felt house value should not be taken into account.

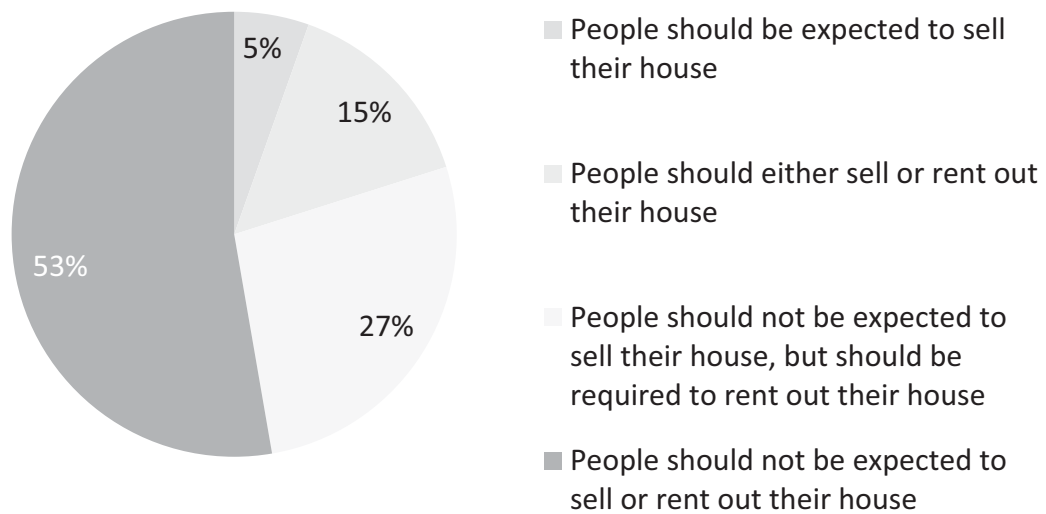


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**40. If houses are taken into account, do you think: a) people should be expected to sell their house; b) peoples should either sell or rent out their house; c) people should not be expected to sell their house, but should be required to rent out their house; OR d) people should not be expect to sell or rent out their house.**

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Over half of respondents (53%) felt that people should not be expected to sell or rent out their house.



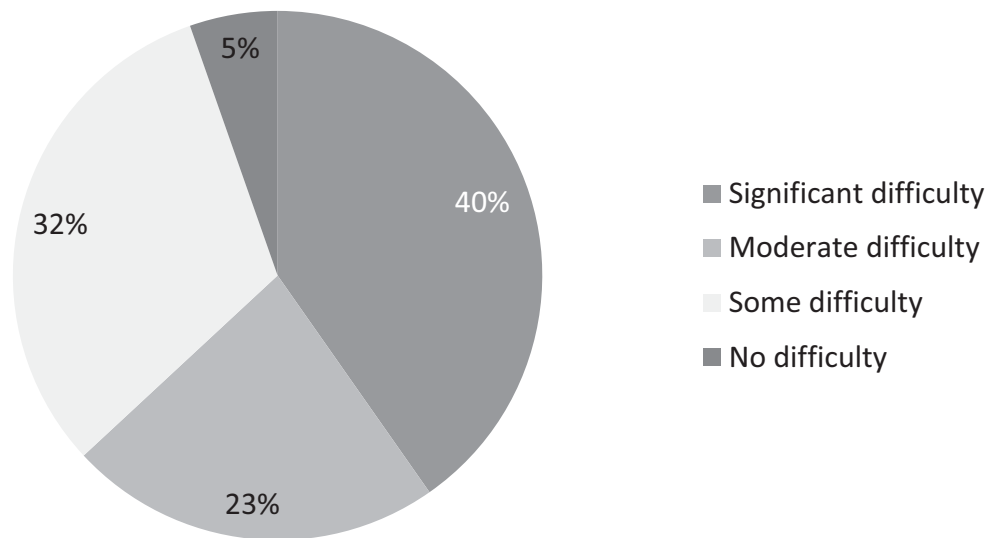
| Answer Choices  | Responses  |                        |
|---|------------|------------------------|
|   | Percentage | Actual no. respondents |
| People should be expected to sell their house   | 5%         | 9                      |
| People should either sell or rent out their house   | 15%        | 28                     |
| People should not be expected to sell their house, but should be required to rent out their house | 27%        | 50                     |
| People should not be expected to sell or rent out their house                                     | 53%        | 97                     |
| <b>Total respondents</b>  |            | 184                    |

Comments included:

- That house sale should only be a last resort.
- That selling or renting should only occur in cases where there were no family/dependents living in the property.
- That sale of a house should always be up to the individual and their family.

#### 41. To what extent do you think people have difficulty securing beds in care homes that they can afford at the moment?

40% of respondents felt that people had significant difficulty securing beds in care homes that they could afford at the moment.



|                               | Significant difficulty | Moderate difficulty | Some difficulty | No difficulty | Total respondents |
|-------------------------------|------------------------|---------------------|-----------------|---------------|-------------------|
| <b>Percentage</b>             | 40%                    | 23%                 | 32%             | 5%            |                   |
| <b>Actual no. respondents</b> | 60                     | 34                  | 47              | 8             | 149               |

Some respondents commented that they felt they did not have a choice of beds but had to take what was available when needed.

It was suggested that the States should identify and negotiate what a reasonable price for a 'States Rates' bed was.

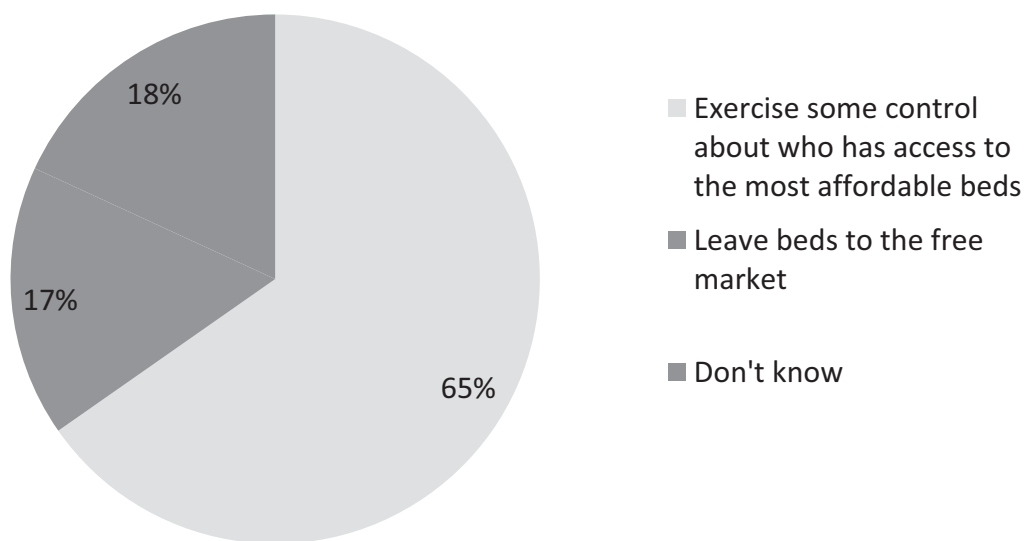
There was general agreement that this was an area that should be looked into further.

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**42. Do you think that the States should think about ways to ensure that affordable beds are made available for people who can't afford to pay top up fees in care homes or do you think it is better to leave this to a free market?**

---

The large majority of respondents (65%) felt that the States should exercise some control about who has access to the most affordable beds.



| Answer Choices   | Responses  |                        |
|--|------------|------------------------|
|  | Percentage | Actual no. respondents |
| Exercise some control about who has access to the most affordable beds | 65%        | 125                    |
| Leave beds to the free market  | 17%        | 32                     |
| Don't know   | 18%        | 35                     |
| <b>Total respondents</b>   |            | 192                    |

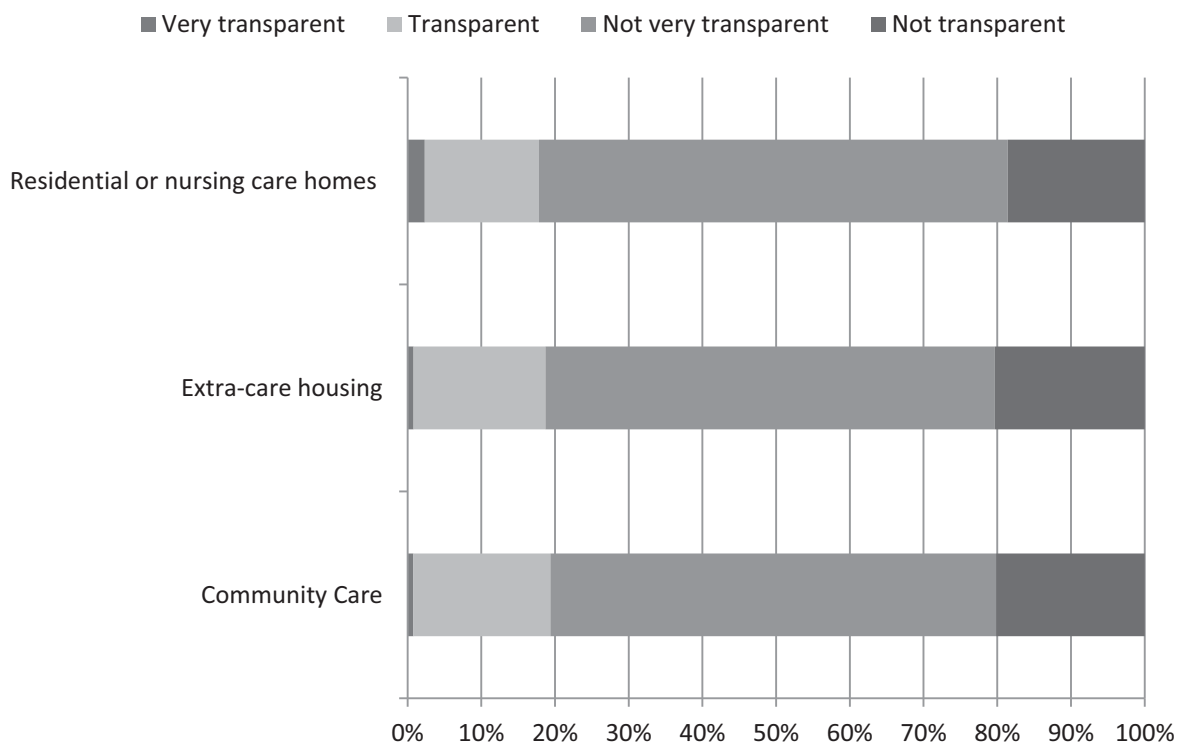
Two respondents felt that the States should provide beds to those who could not afford placements and should expand public sector provision to do so, if required.

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### 43. To what extent do you feel eligibility criteria for services are transparent or not transparent at the moment?

---

Over half of respondents felt that eligibility criteria for services were not very transparent at the moment.



|  | <b>Very transparent</b> | <b>Transparent</b> | <b>Not very transparent</b> | <b>Not transparent</b> | <b>Total respondents</b> |
|--|-------------------------|--------------------|-----------------------------|------------------------|--------------------------|
| <b>Community Care</b>                    | 1%<br>1                 | 19%<br>24          | 60%<br>78                   | 20%<br>26              | 129                      |
| <b>Extra-care housing</b>                | 1%<br>1                 | 18%<br>22          | 61%<br>75                   | 20%<br>25              | 123                      |
| <b>Residential or nursing care homes</b> | 2%<br>3                 | 15%<br>19          | 64%<br>82                   | 19%<br>24              | 128                      |

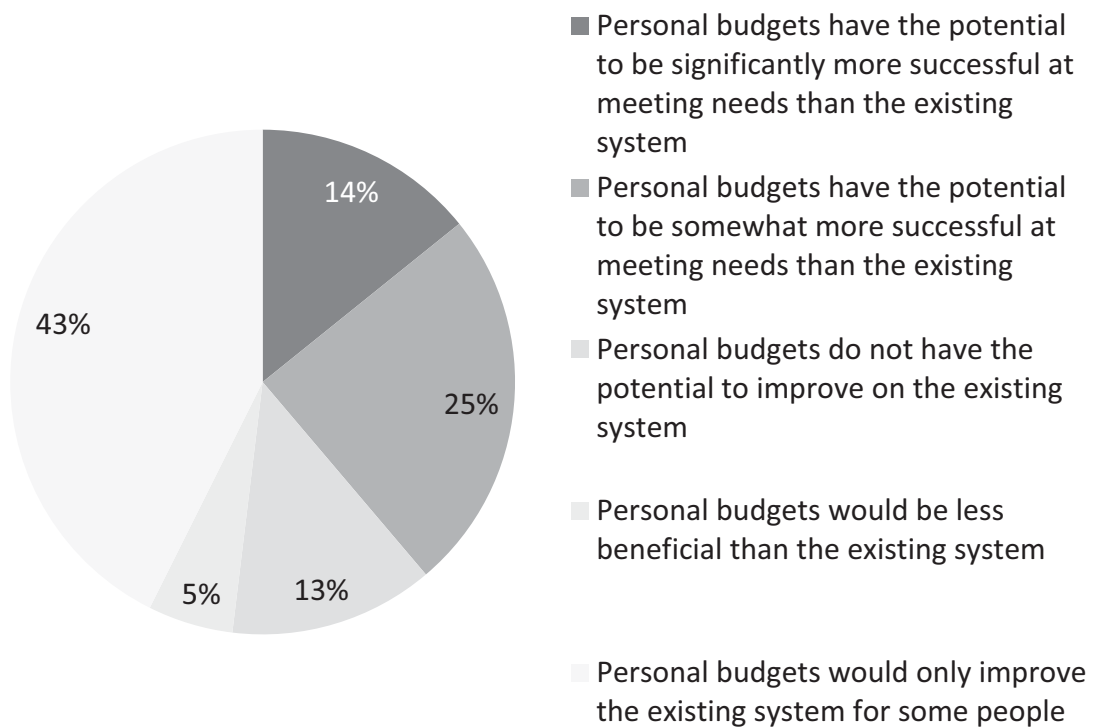
There were some concerns that the current eligibility processes and the operation of the Needs Assessment Panel were not transparent.

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## 44. What do you think about personal budgets and their benefits?

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A significant number of respondents (43%) felt that personal budgets would only improve the existing system for some people.





| Answer Choices  | Responses  |                        |
|---|------------|------------------------|
|   | Percentage | Actual no. respondents |
| Personal budgets have the potential to be significantly more successful at meeting needs than the existing system | 14%        | 25                     |
| Personal budgets have the potential to be somewhat more successful at meeting needs than the existing system      | 25%        | 45                     |
| Personal budgets do not have the potential to improve on the existing system                                      | 13%        | 24                     |
| Personal budgets would be less beneficial than the existing system  | 5%         | 10                     |
| Personal budgets would only improve the existing system for some people   | 43%        | 79                     |
| <b>Total respondents</b>  |            | <b>183</b>             |

There was some support for the idea that personal budgets would give people more choice and flexibility.

Some respondents felt that consumer choice could drive service improvements.

It was felt that it would be a positive step for disabled people to be trusted to make choices.

It was considered that personal budgets would need to be tested or piloted before being introduced universally.

There were some cases in which people were caring for family members at home that had high need levels and could be admitted to a care home, but because their family chose to keep them at home they received minimal financial support, and this did not seem fair.

Some respondents felt that personal budgets amounted to privatisation and that this was undesirable and would drive up costs.

There were concerns about:

- People not wanting the responsibility, or wanting varying degrees of responsibility – if personal budgets were introduced there would need to be a range of options for receiving such funding.

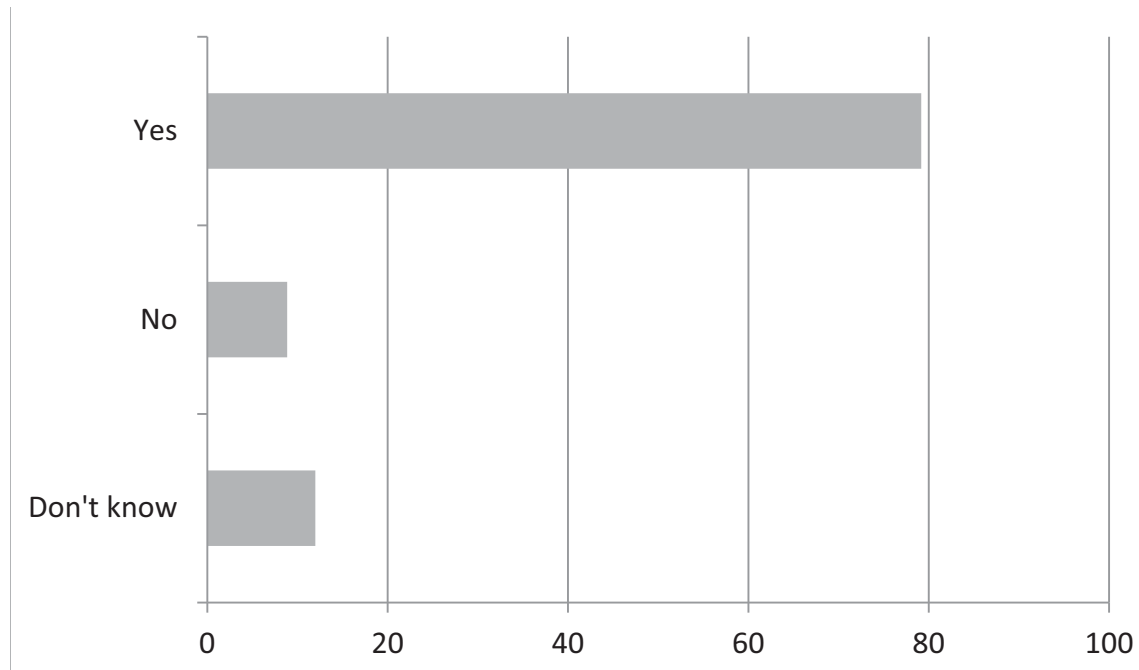
- Administrative problems.
- Capacity issues (i.e. whether or not people had the skills and cognitive capacity to manage their finances).
- Fraud or inappropriate spending.
- The possibility of need for development in the third sector, as some organisations which are currently voluntary could begin to consider employing staff.
- The risk of the exploitation of an individual's budget by carers or care staff.
- The lack of a market from which to buy services, since there were few existing providers of domiciliary care and support in the private and third sector.
- The variable demand for services which could make service provision challenging.
- The lack of knowledge amongst the public about what personal budgets were or what they could be used for, which might cause implementation issues.
- The need for information, advice and support to use personal budgets if they were introduced.
- Certain kinds of spending, e.g. on equipment, would benefit from professional advice to ensure that the right kind was bought – there could be a risk that in trying to save money individuals would buy products that did not support their health.
- The level of media interest that could be targeted on personal budget holders.
- Whether or not money from personal budgets could be spent off-island.
- Personal budgets not achieving economies of scale.
- Personal budgets not working well in the UK.
- The need for ongoing routine assessments to check the level of payment was correct.
- Outcome surveys, monitoring and inspection would be required.
- There would need to be quality assurance over service providers that could be accessed via personal budgets.

---

**45. Some private and third sector care providers provide care in people's own homes. Do you think that a grant or benefit should be made available to fund this type of care?**

---

The majority of respondents (79%) thought that a grant or benefit should be made available to fund this type of care.



| Answer Choices    | Responses  |                        |
|-------------------|------------|------------------------|
|                   | Percentage | Actual no. respondents |
| Yes               | 79%        | 152                    |
| No                | 9%         | 17                     |
| Don't know        | 12%        | 23                     |
| Total respondents |            | 192                    |

There were few comments on this, but those that were received were mostly supportive. One person commented that it was unfair that a person self-funding their own care in their own home was still required to pay Long-term Care Insurance contributions. There were also comments about the need to monitor the quality,

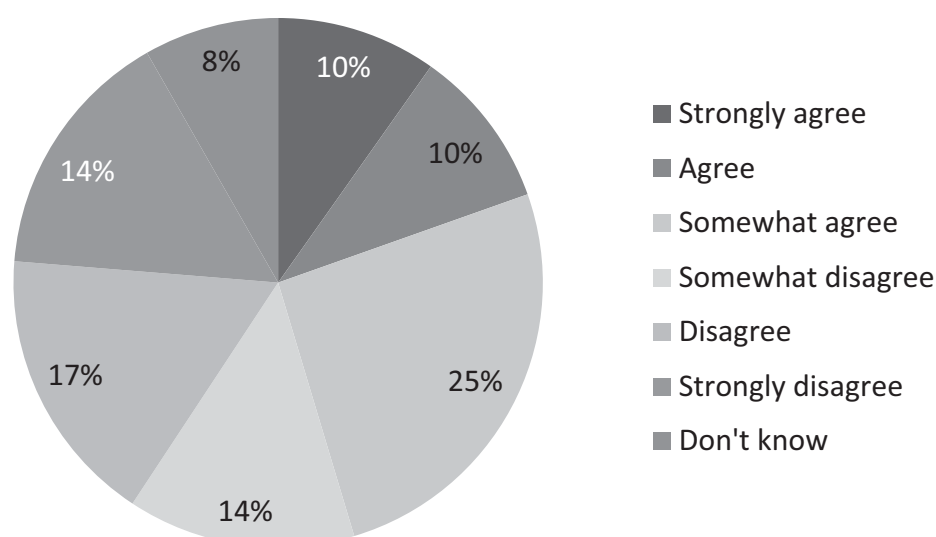
outcomes etc. of care in the private and third sector, and to ensure that what was being paid for was value for money.

---

#### 46. To what extent do you agree or disagree that people should be given a direct payment in order to manage their own care provision rather than paying the providers directly?

---

Opinion was divided between those who agreed (45%) with the principle of direct payments and those who disagreed (46%).



| Answer Choices    | Responses  |                        |
|-------------------|------------|------------------------|
|                   | Percentage | Actual no. respondents |
| Strongly agree    | 10%        | 19                     |
| Agree             | 10%        | 19                     |
| Somewhat agree    | 25%        | 49                     |
| Somewhat disagree | 14%        | 27                     |
| Disagree          | 17%        | 33                     |
| Strongly disagree | 16%        | 30                     |
| Don't know        | 8%         | 16                     |
| Total respondents |            | 193                    |

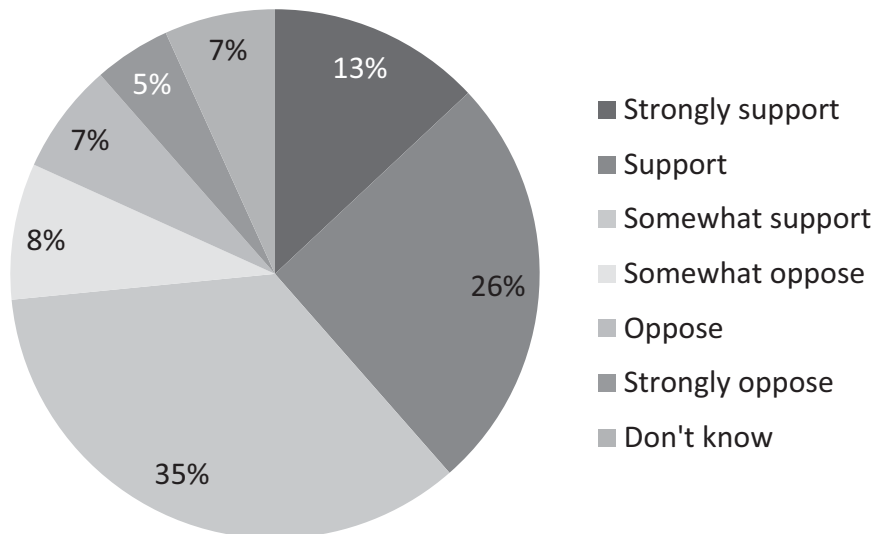
There were some comments that the success of direct payments would depend on the capacity of the person in receipt of the payment to manage their own finances.

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**47. Hypothetically, if personal budgets were introduced, to what extent would you support or oppose the use of personal budgets to pay family members who are carers for the caring that they undertake?**

---

The majority of respondents (73%) supported the use of personal budgets to pay family members who are carers for the caring that they undertook.



|                               | Strongly Support | Support | Somewhat Support | Somewhat oppose | Oppose | Strongly oppose | Don't know | Total respondents |
|-------------------------------|------------------|---------|------------------|-----------------|--------|-----------------|------------|-------------------|
| <b>Percentage</b>             | 13%              | 26%     | 35%              | 8%              | 7%     | 5%              | 7%         |                   |
| <b>Actual no. respondents</b> | 25               | 49      | 67               | 16              | 13     | 9               | 13         | 192               |

There was a concern that if this was to be pursued it would need to be monitored carefully to prevent abuse.

One respondent commented that they would find such a system confusing.

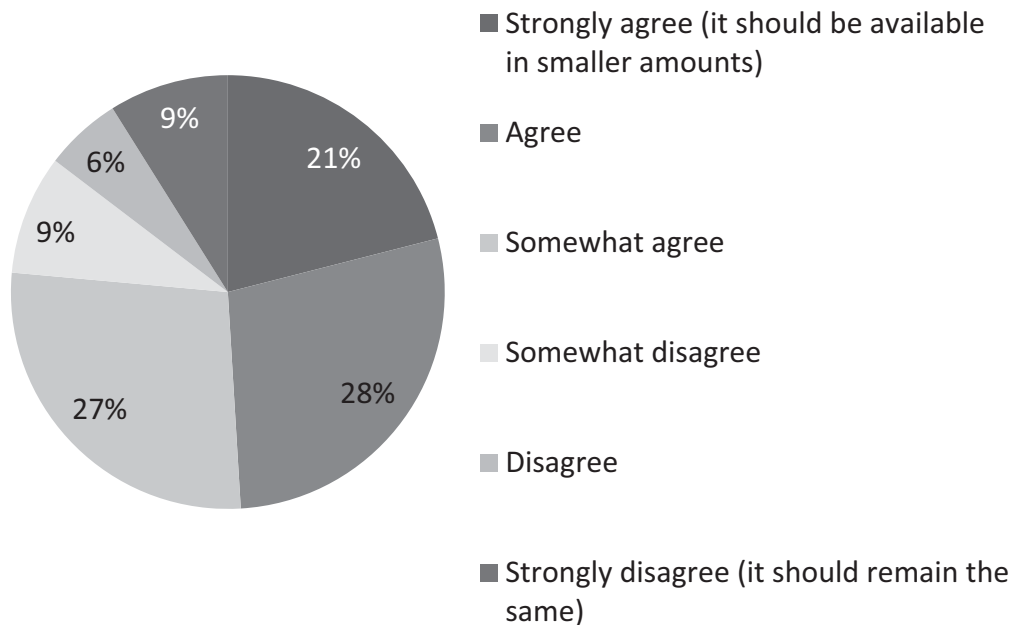
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#### 48. To what extent do you agree or disagree that Severe Disability Benefit should be reviewed and reconfigured so that it is accessible in smaller amounts to people with less severe disabilities?

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The majority of respondents (76%) somewhat agreed, agreed or strongly agreed that Severe Disability Benefit should be reviewed and reconfigured so that it was accessible in smaller amounts to people with less severe disabilities.

More Alderney respondents (40%) strongly disagreed that Severe Disability Benefit should be reviewed and reconfigured so that it was accessible in small amounts to people with less severe disabilities.



|                              | Strongly agree | Agree | Somewhat agree | Somewhat disagree | Disagree | Strongly disagree | Total respondents |
|------------------------------|----------------|-------|----------------|-------------------|----------|-------------------|-------------------|
| <b>Percentage</b>            | 21%            | 28%   | 27%            | 9%                | 6%       | 9%                |                   |
| <b>Total no. respondents</b> | 33             | 44    | 43             | 14                | 9        | 14                | 157               |

There were questions raised about the clarity of the current need threshold determining who was and who was not 'severely disabled'.

Some respondents expressed support for having tiers or levels of benefit.

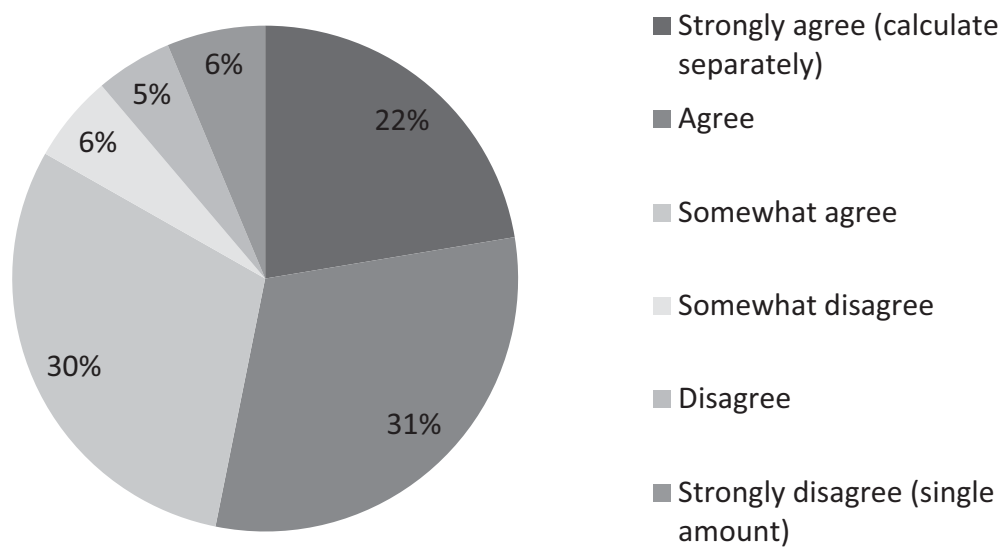
It was felt that Severe Disability Benefit should remain separate from personal budgets if they were introduced.

---

**49. To what extent do you agree or disagree that Severe Disability Benefit should be calculated separately for costs associated with mobility and for costs associated with increased living costs associated with having a disability?**

---

The vast majority of respondents (83%) somewhat agreed, agreed or strongly agreed that Severe Disability Benefit should be calculated separately for costs associated with mobility and for costs associated with increased living costs associated with having a disability.





|                   | Strongly agree<br>(calculate<br>separately) | Agree | Somewhat<br>agree | Somewhat<br>disagree | Disagree | Strongly<br>Disagree (single<br>amount) | Total |
|-------------------|---|-------|-------------------|----------------------|----------|---|-------|
| <b>Percentage</b> | 22%   | 31%   | 30%               | 6%                   | 5%       | 6%                                      |       |
| <b>Actual</b>     | 32  | 44    | 43                | 8                    | 7        | 9                                       | 193   |

It was noted that Severe Disability Benefit was not always used to pay for 'care services' and that the living costs it covered included transport, laundry, equipment, supplies related to the impairment, cleaning, heating and gardening.

Some respondents felt that the current weekly benefit of £98.98 was insufficient to provide any notable amount of care.

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## 50. Would you like to say anything else about funding?

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### Charging for community services

There was one respondent who felt that the services which HSSD provided in the community should be charged for; and where there were already charges, that these should be increased.

### Carer's Allowance

There were concerns that carers were not aware of the existence of Carer's Allowance.

There were questions over whether the 35 hour threshold was appropriate.

The amount offered (£80.08 per week, 2015) was felt by some respondents not to be adequate compensation for 35 hours' care work. Others felt that it was too generous.

### Legality of changing the Long-term Care Insurance Scheme

Concerns were raised over the legality of changing the parameters of the Long-term Care Insurance Scheme after a decade or more of operation.

There were concerns about whether some individuals who stayed in the Islands for a short period of time would contribute to the Fund but not stand to gain from it, and whether this was fair.

### **Security vs precariousness**

One organisation commented that whilst the particular funding arrangements were a moot point, whatever system was established should seek to provide enough security to promote wellbeing.

### **Downsizing**

It was suggested that ensuring there were more properties suitable for downsizing would enable people to release capital to pay for their own care.

### **Old age poverty**

Old age poverty was a concern, and there were some who raised issues about the increasing cost of living and poor returns on investments leaving older people in a less secure financial position than they had planned for. This raised some concerns about the risks of poverty in old age and the number of people who would be in a position to fund their care if means-testing were expanded.

### **Residency requirement**

One person commented that they felt that the five year residency requirement for accessing the Long-term Care Insurance Scheme was too low.

### **GP visits**

The cost of home visits from GPs was a concern to some – including to those resident in care homes.

### **Prioritisation**

Some respondents were concerned that some of the proposals in the consultation document would increase costs: this would not be realistic and tough decisions would need to be made about prioritising change.

### **Other means of raising funds suggested**

Some respondents suggested alternative means of raising funds, including:

- Further reducing the number of Deputies and freezing Deputies' pay.
- Allocating funds raised through lottery profits.

- Withdrawing funding from the Ecclesiastical Court.
- Charging rent to Church of England properties.
- Withdrawing funding from the Transport Strategy, Waste Strategy and buses.
- Increasing taxes for higher earners/removing the tax cap.
- Revisiting zero/10.
- Reducing senior management pay in the civil service.
- Reducing the cost of public-sector occupational pensions.
- Reviewing Magistrates' pay.
- Reducing the amount of spending on capital projects; school builds were specifically mentioned.
- Arranging work-experience for those people on Unemployment Benefit to undertake some of the low-level work currently done by States departments.
- Undertaking a value for money review of current services, including care home charges.
- Introducing inheritance tax.
- Reducing the rate of some benefits.

## Information about respondents

Questions 51 to 54 show that the majority of respondents were concerned members of the public of pre-retirement age living in Guernsey. More women than men responded.

### 51. I am responding on behalf of (select all that apply):

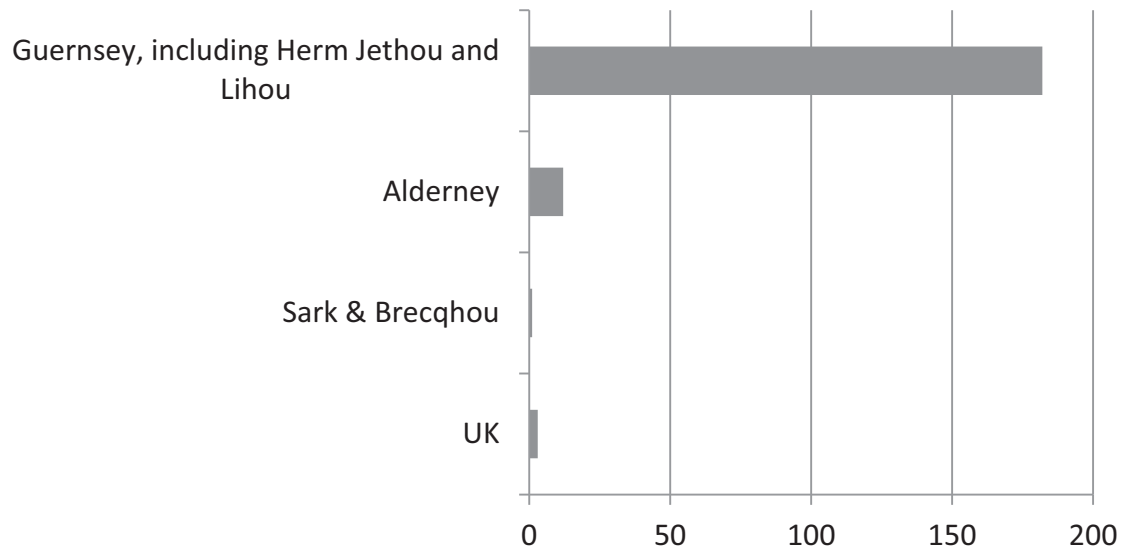


Some comments were received in the 'other' field. Most of these related to individuals who had been carers or were retired professionals.

| Answer Choices  | Reponses   |                        |
|---|------------|------------------------|
|   | Percentage | Actual no. respondents |
| Myself – I am a person with care and support needs                      | 9%         | 18                     |
| Myself – I care for a friend or family member (I am a carer)            | 15%        | 29                     |
| Myself – I am a concerned member of the public                          | 14%        | 28                     |
| On behalf of a friend or relative with care and support needs           | 55%        | 108                    |
| A third sector or community organisation, charity or support group      | 17%        | 34                     |
| A third sector or community organisation, charity or support group      | 13%        | 26                     |
| A private or third sector care provider or specialised housing provider | 2%         | 3                      |
| An organisation of health professionals                                 | 2%         | 4                      |
| A unit, section or department of the public sector                      | 5%         | 9                      |
| A business organisation not directly involved in care                   | 0%         | 0                      |
| <b>Total respondents</b>  |            | <b>196</b>             |

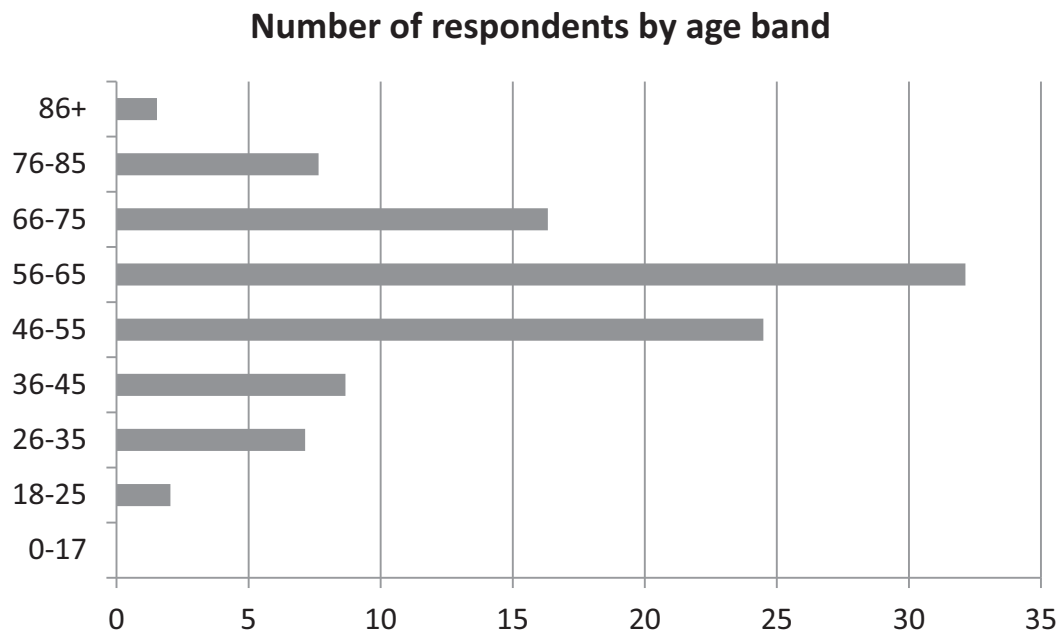
## 52. Where do you live, or if you are responding on behalf of an organisation where do you operate?

**Number of respondents by geographical location**



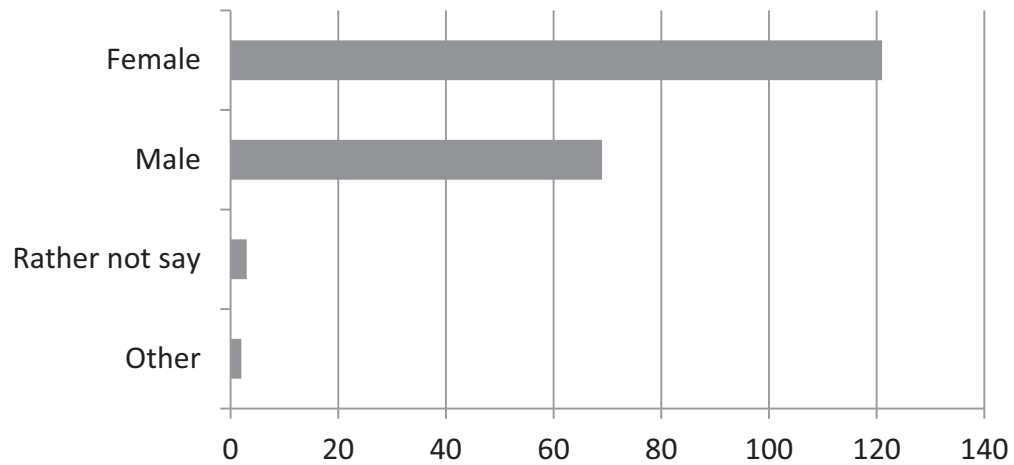
| Answer Choices                            | Responses  |                        |
|---|------------|------------------------|
|   | Percentage | Actual no. respondents |
| Guernsey, including Herm Jethou and Lihou | 93%        | 182                    |
| Alderney                                  | 6%         | 12                     |
| Sark & Brecqhou                           | 1%         | 1                      |
| UK  | 2%         | 3                      |
| Total respondents                         |            | 196                    |

## 53. What is your age?



| Answer Choices    | Responses  |                        |
|-------------------|------------|------------------------|
|                   | Percentage | Actual no. respondents |
| 0-17              | 0%         | 0                      |
| 18-25             | 2%         | 4                      |
| 26-35             | 7%         | 14                     |
| 36-45             | 9%         | 17                     |
| 46-55             | 24%        | 48                     |
| 56-65             | 32%        | 63                     |
| 66-75             | 16%        | 32                     |
| 76-85             | 8%         | 15                     |
| 86+               | 2%         | 3                      |
| Total respondents |            | 196                    |

## 54. What is your gender?



| Answer Choices              | Responses  |                        |
|-----------------------------|------------|------------------------|
|                             | Percentage | Actual no. respondents |
| Female                      | 62%        | 121                    |
| Male                        | 35%        | 69                     |
| Rather not say              | 2%         | 3                      |
| Other: Multiple respondents | 1%         | 2                      |
| Total respondents           |            | 195                    |

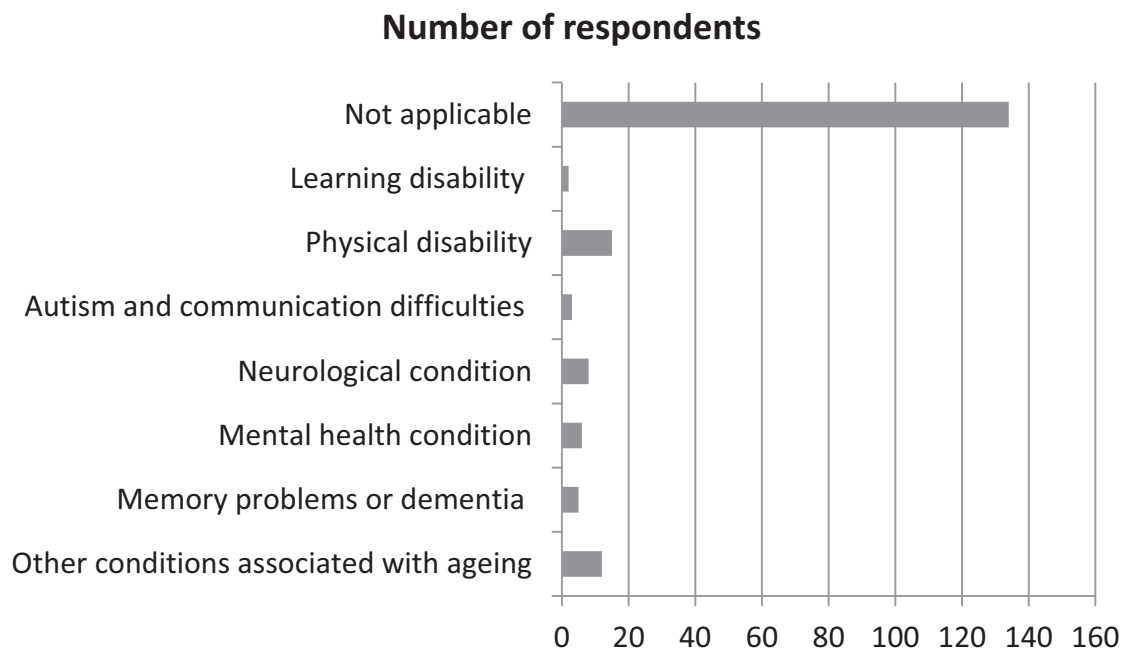


Questions 55 and 56 show us that most respondents did not report having care or support needs; however, there were a few respondents in each category of long-term condition listed. Of those with care and support needs most lived in their own home with a couple in supported housing, care homes or other settings.

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**55. If you have care and support needs, what best describes your long-term condition (tick all that are applicable)?**

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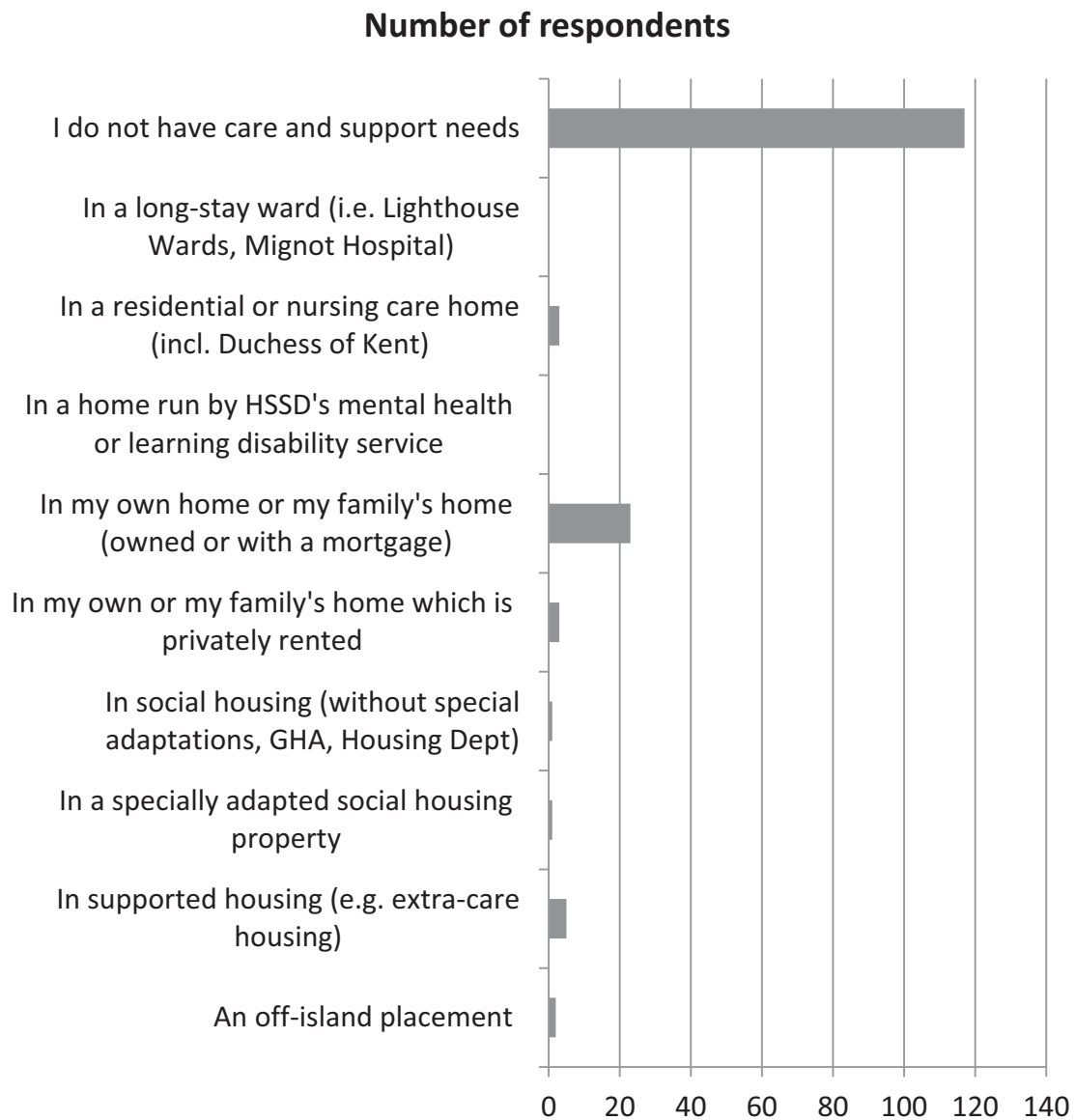
| Answer Choices   | Responses  |                        |
|--|------------|------------------------|
|  | Percentage | Actual no. respondents |
| Not applicable – I do not have care and support needs  | 78%        | 134                    |
| Learning disability  | 1%         | 2                      |
| Physical disability (including e.g. heart, lungs, spinal injuries, sensory impairments, chronic illness) | 9%         | 15                     |
| Autism and communication difficulties  | 2%         | 3                      |
| Neurological condition (e.g. stroke, MS, Parkinson's)  | 5%         | 8                      |
| Mental health conditions (except dementia)   | 4%         | 6                      |
| Memory problems or dementia  | 3%         | 5                      |
| Other conditions associated with ageing  | 7%         | 12                     |
| <b>Total respondents</b>   |            | <b>171</b>             |

Where listed, 'other' conditions were categorised and incorporated into the responses where appropriate. (N.B. brain injuries and cognitive impairments due to illness and injury have been incorporated into 'neurological conditions', though queries were raised about this grouping.)

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**56. If you are a person with care and support needs, what type of accommodation do you live in?**

---



| Answer Choices   | Responses  |                        |
|--|------------|------------------------|
|  | Percentage | Actual no. respondents |
| I do not have care or support needs                                  | 75%        | 117                    |
| In a long-stay ward (i.e. Lighthouse Wards, Mignot Hospital)         | 0%         | 0                      |
| In a residential or nursing care home (incl. Duchess of Kent)        | 19%        | 3                      |
| In a home run by HSSD's mental health or learning disability service | 0%         | 0                      |
| In my own home or my family's home (owned or with a mortgage)        | 15%        | 23                     |
| In my own or my family's home which is privately rented              | 2%         | 3                      |
| In social housing (without special adaptation, GHA, Housing Dept)    | 1%         | 1                      |
| In a specially adapted social housing property                       | 1%         | 1                      |
| In supported housing (e.g. extra-care housing)                       | 3%         | 5                      |
| An off-island placement  | 1%         | 2                      |
| Total respondents  |            | 155                    |

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## 57. Name of organisation you are responding on behalf of (if applicable):

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The following organisations were named respondents to the survey:

- Age Concern
- Autism and ADHD Support Groups
- Alderney: Age Concern, Home Help Scheme, Connaught Care Home and Milly's Foundation
- Guernsey Disability Alliance
- GSF (Mental Health Charity)
- Ageing Well in the Bailiwick
- MS Society

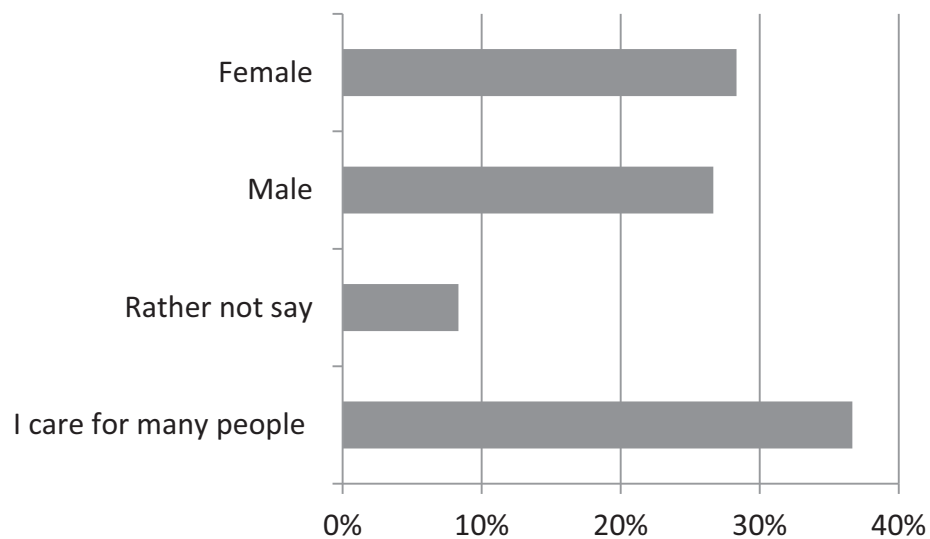
- Guernsey Housing Association
- Health Intelligence Unit, HSSD
- Learning Disability Life-Skills Maintenance Group
- Headway Guernsey

Formal written responses were additionally received from the following organisations:

- Ageing Well in the Bailiwick
- Alderney Age Concern, Home Help Scheme, Connaught Care Home and Milly's Foundation
- Autism Guernsey
- Guernsey Care Homes (Holdings) Limited
- Guernsey Care Managers Association
- Guernsey Disability Alliance
- Guernsey Hard of Hearing Association
- Guernsey Sheltered Housing Group
- MENCAP
- Primary Care Committee
- Wigwam

People who formally or informally cared reported caring for people of a range of ages and conditions and in a range of care settings. The largest group were older people living in their own homes.

## 58. What is the gender of the person/people you care for or support:

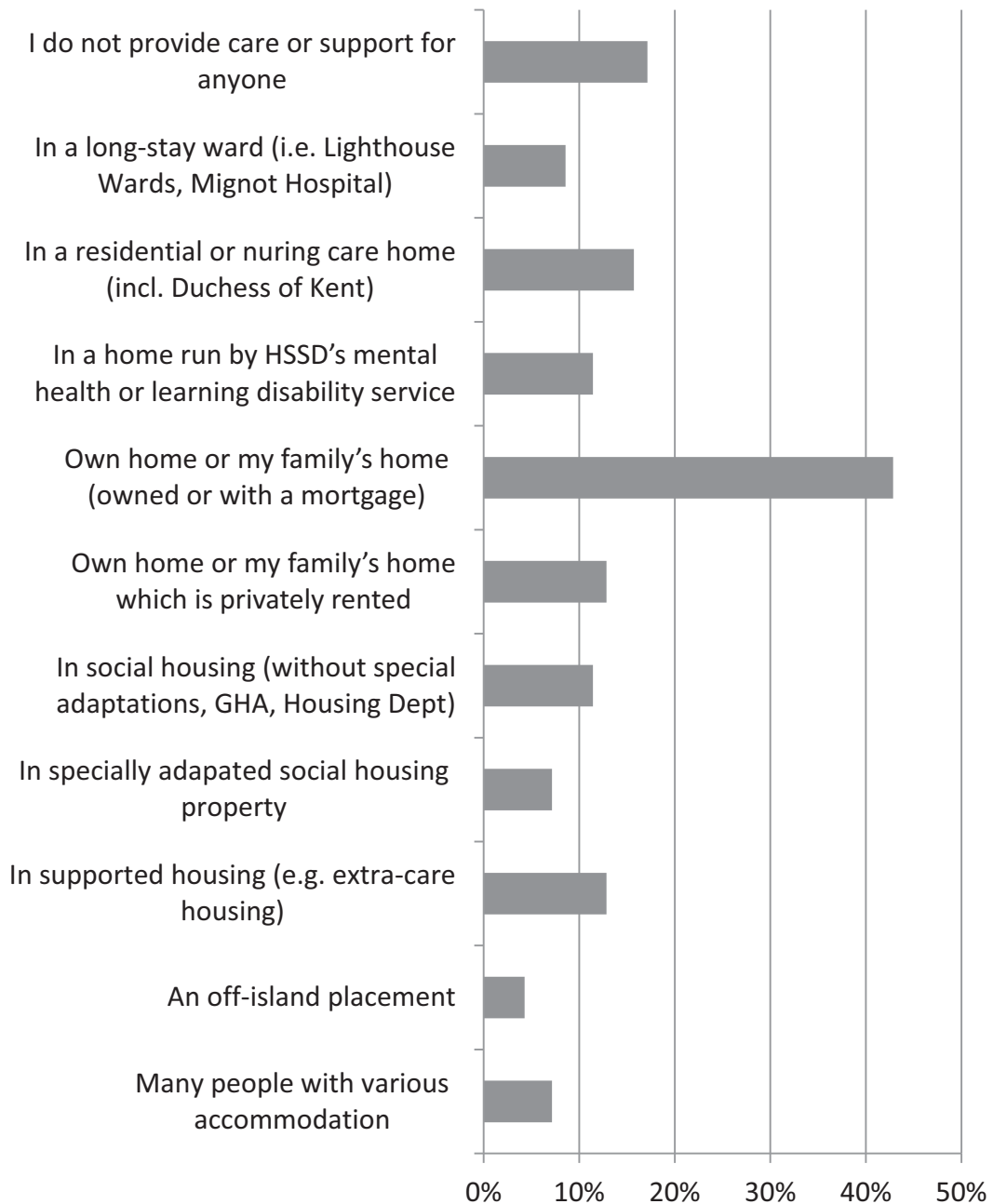


| Answer Choices         | Responses  |                        |
|------------------------|------------|------------------------|
|                        | Percentage | Actual no. respondents |
| Female                 | 32%        | 17                     |
| Male                   | 28%        | 16                     |
| Rather not say         | 9%         | 5                      |
| I care for many people | 32%        | 22                     |
| Total respondents      |            | 60                     |

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**59. What type of accommodation do the person/people you care for or support live in (tick all that apply):**

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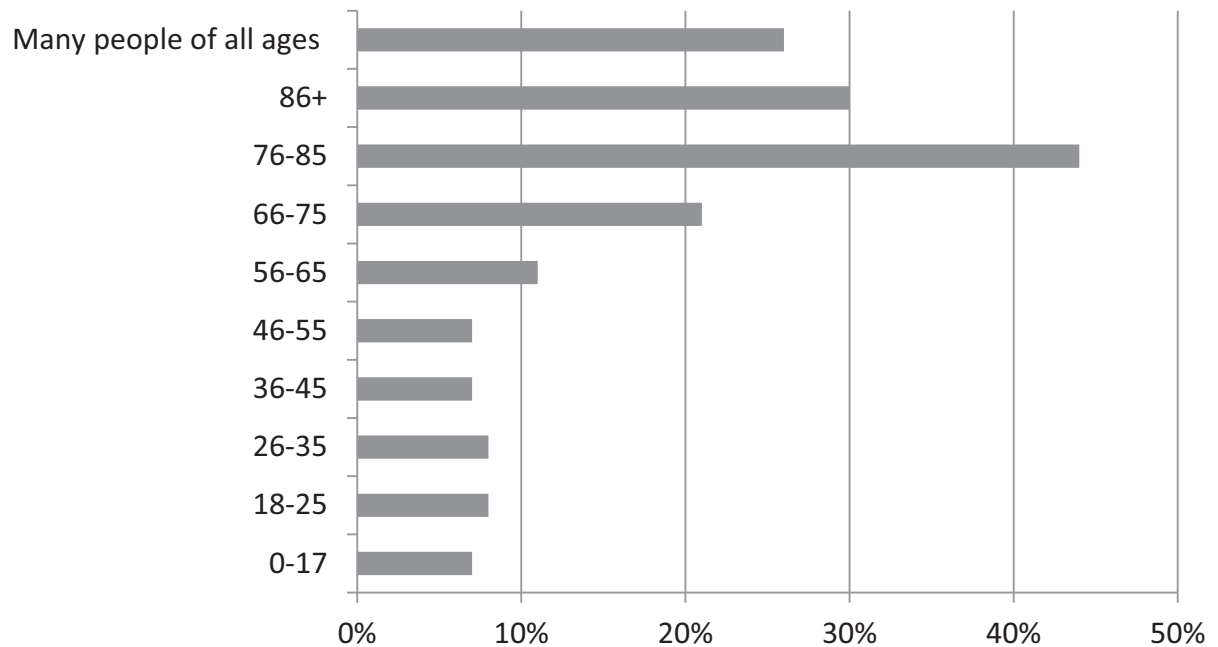
| Answer Choices  | Responses  |                        |
|---|------------|------------------------|
|   | Percentage | Actual no. respondents |
| I do not provide care or support for anyone                           | 17%        | 12                     |
| In a long-stay ward (i.e. Lighthouse Wards, Mignot Hospital)          | 9%         | 6                      |
| In a residential or nursing care home (incl. Duchess of Kent)         | 16%        | 11                     |
| In a home run by HSSD's mental health or learning disability service  | 11%        | 8                      |
| In my [their] own home or my family's home (owned or with a mortgage) | 43%        | 30                     |
| In my [their] own home or my family's home which is privately rented  | 13%        | 9                      |
| In social housing (without special adaptations, GHA, Housing Dept)    | 11%        | 8                      |
| In specially adapted social housing property                          | 7%         | 5                      |
| In supported housing (e.g. extra-care housing)                        | 13%        | 9                      |
| An off-island placement   | 4%         | 3                      |
| Many people with various accommodation                                | 7%         | 5                      |
| <b>Total respondents</b>  |            | <b>70</b>              |



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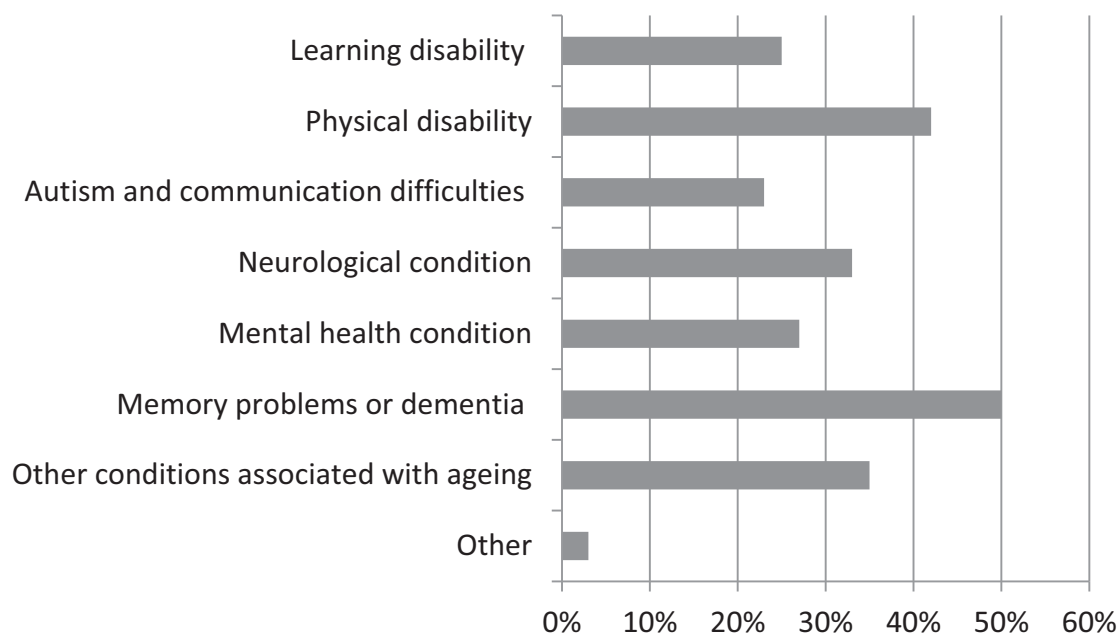
**60. What is the age group of the person/people you care for or support (tick all that apply):**

---



| Answer Choices   | Responses  |                        |
|--|------------|------------------------|
|  | Percentage | Actual no. respondents |
| <b>0-17</b>  | 7%         | 4                      |
| <b>18-25</b>   | 8%         | 5                      |
| <b>26-35</b>   | 8%         | 5                      |
| <b>36-45</b>   | 7%         | 4                      |
| <b>46-55</b>   | 7%         | 4                      |
| <b>56-65</b>   | 11%        | 7                      |
| <b>66-75</b>   | 21%        | 13                     |
| <b>76-85</b>   | 44%        | 27                     |
| <b>86+</b>   | 30%        | 18                     |
| <b>I/my organisation care(s) for many people of all ages</b> | 26%        | 16                     |
| <b>Total respondents</b>                                     |            | <b>61</b>              |

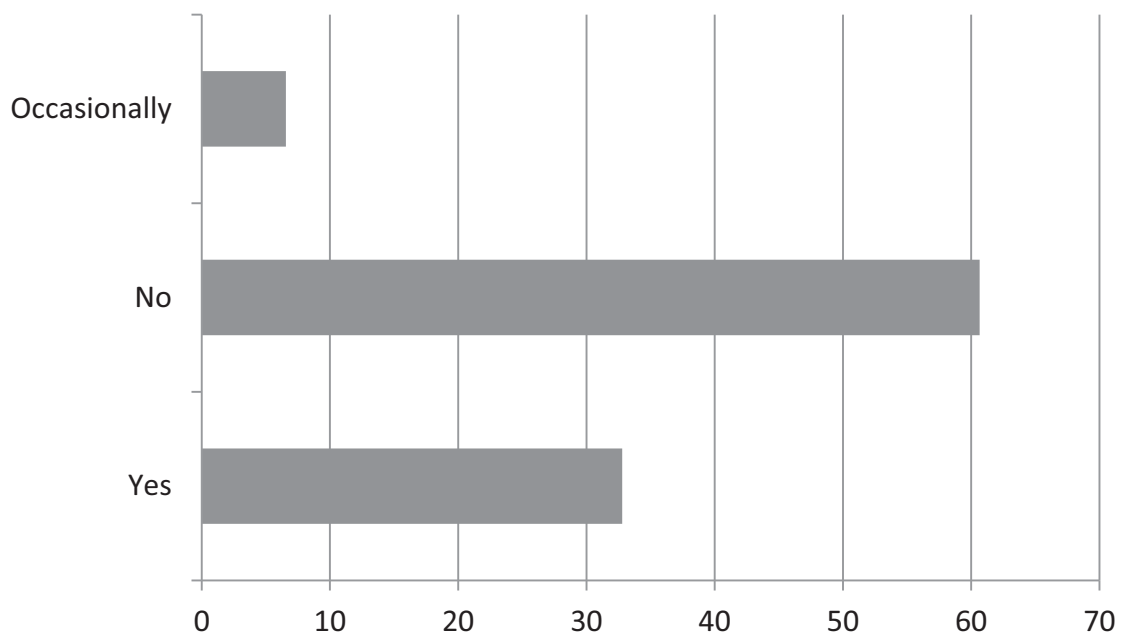
**61. What best describes the condition of the person/people you care for or support (tick all that are applicable)?**



| Answer Choices   | Responses  |                        |
|--|------------|------------------------|
|  | Percentage | Actual no. respondents |
| Learning disability  | 25%        | 15                     |
| Physical disability (including e.g. heart, lungs, spinal injuries, sensory impairments, chronic illness) | 42%        | 25                     |
| Autism and communication difficulties  | 23%        | 14                     |
| Neurological condition (e.g. stroke, MS, Parkinson's)  | 33%        | 20                     |
| Mental health conditions (except dementia)   | 27%        | 16                     |
| Memory problems or dementia  | 50%        | 30                     |
| Other conditions associated with ageing  | 35%        | 21                     |
| Other  | 3%         | 2                      |
| <b>Total respondents</b>   |            | <b>60</b>              |

For the purposes of this categorisation people with brain injury or who had had a stroke were grouped with neurological conditions. One comment was made that it was inaccurate to class a stroke as a neurological condition and this should be considered a physical disability.

## 62. Do you live with the person/people you care for or support?



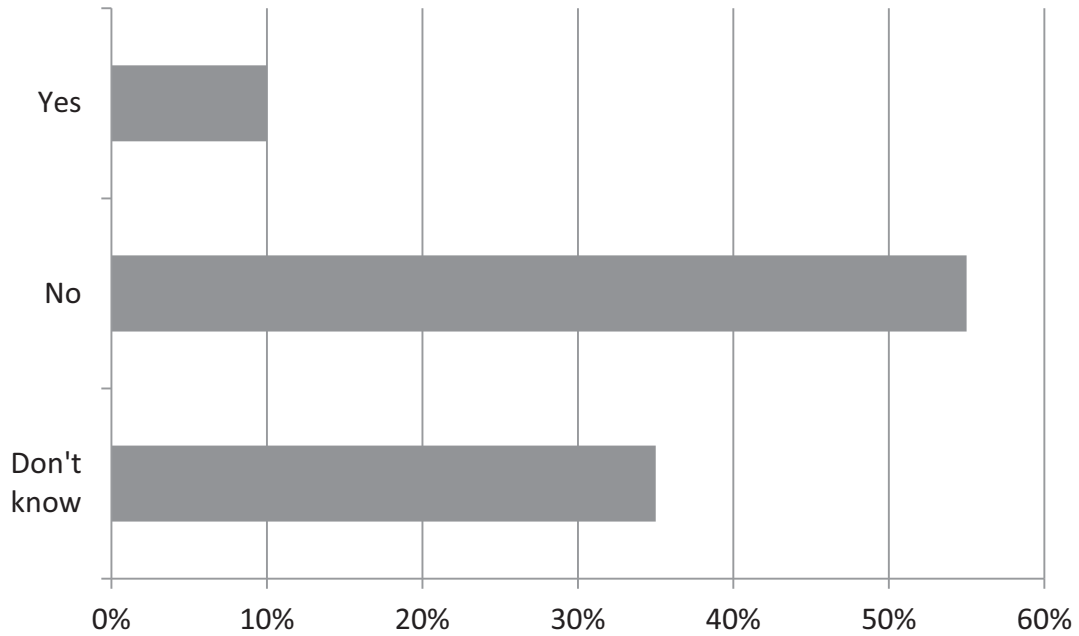
| Answer Choices                  | Responses  |                        |
|---------------------------------|------------|------------------------|
|                                 | Percentage | Actual no. respondents |
| Yes                             | 34%        | 20                     |
| No                              | 63%        | 37                     |
| Occasionally, if so, how often? | 3%         | 2                      |
| Total                           |            | 59                     |

Of those who lived with the person they cared for occasionally one responded 'when ill' the other 'every two months or so'.

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**63. Did any of the people you care for or support also complete this consultation document?**

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| Answer choices | Responses  |                        |
|----------------|------------|------------------------|
|                | Percentage | Actual no. respondents |
| Yes            | 10%        | 6                      |
| No             | 55%        | 33                     |
| Don't know     | 35%        | 21                     |
| Total          |            | 60                     |

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## 64. Further comments

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### **General support**

Some comments were made offering general support for the direction of the Strategy.

### **Age appropriate care**

Concerns were raised by some about the need for age-appropriate care settings for younger adults with physical impairments, as there had been cases where these individuals had been cared for in settings primarily targeted at older adults.

### **Building care around personal relationships**

Several respondents commented on the need to build care around personal relationships. There were concerns about cases where couples were split up in order that one of them could be provided with a high level of care in a residential setting. There were concerns about Alderney residents being isolated when being cared for or treated in Guernsey due to lack of facilities for visiting family members. Some older people may have younger dependents who they wish to continue caring for – it was felt that the possibility of having extra-care housing which could, for example, house an elderly couple and a younger person with a learning disability together would be important, if they wished to live together.

### **Continuity of care staff and staff retention**

Several respondents were concerned about the need for care staff to be able to get to know the people they were working with, and for there to be stability and continuity in which staff visited and interacted with service users.

### **Transition**

There were significant concerns about the need for improved management of transition for young people into adult services. There were concerns that some young people who received significant support as teenagers would find that they would not qualify for adult services and that the change from children and young people's services to adult services was too abrupt. The lack of communication to young people and their parents or guardians about transition and what lay ahead of them was also a concern.

### **Cost of living**

The cost of living on the islands was a concern, with Alderney residents raising particular concerns about the fact that their cost of living was even higher than in Guernsey.

### **Working population increase**

Some respondents suggested seeking to increase the working population or to attract younger people to improve the dependency ratio. There was also a suggestion that an increase in retirement age could help to improve the situation.

### **Care to boost the economy**

It was suggested that there may be opportunities to improve Guernsey's economy if care services supported people with disabilities and their carers to work. There was also the suggestion that the care sector could generate income if there was world-class care available and wealthy self-funders could be attracted to the island in order to receive care.

### **End of life care**

There were some concerns that nursing homes should more strongly link with end of life care provision, as many of the residents are approaching the end of their lives.

### **Lasting powers of attorney**

Some comments were made on the need for lasting powers of attorney and living wills.

### **Waiting times and coordination for specialist appointments**

There were a couple of comments which raised concerns about waiting times and coordination of specialist appointments.

### **Adult education**

Ongoing support and education for young adults to support them to gain life skills and live independently was felt to be needed – particularly at 'transition' into independent living. There were also calls for courses for older people, particularly to enable them to use helpful technology that could allow them to stay in touch better.

### **Prescription charges**

There were some concerns about plans to withdraw prescription charges.

### **Specialist care vs general provision**

A couple of respondents highlighted the importance of pursuing specialist care focused on specific conditions rather than generic, one-size-fits-all care.

### **Staffing of care services**

There were concerns both about existing staffing levels, staff retention, possible future staffing shortages, local availability of training and the different qualification levels available to staff. There was some concern that care staff were under-valued and that they were affected by housing license issues and accommodation availability (especially with regard to changes in the occupancy of Open Market properties).

### **Transport and accessibility**

There were some concerns about transport issues and the accessibility of public venues for people with disabilities.

### **Complex needs**

There were particular concerns about the management of cases of people with complex or multiple needs.

### **Healthcare**

There were some concerns about the most effective balance of specialist provision on Guernsey and to what extent on-Island specialists were effective.

### **Domestic abuse**

There was a comment about the lack of availability of safe houses for male survivors of domestic abuse.

### **Encouraging people to ask for help**

There was some concern that some people with support needs would not ask for help or accept help even if they needed it. Their denial of their needs could place family members in difficult situations.

### **Equipment provision**

There were concerns about the availability of equipment and the existing system for accessing and funding equipment (including wheelchairs), which was highlighted as key to supporting independent living.

**Email:** [slaws@gov.gg](mailto:slaws@gov.gg)

**Address:** The Supported Living and Ageing Well Strategy  
Policy Council  
Sir Charles Frossard House  
La Charroterie  
St Peter Port  
GY1 1FH

**Telephone:** 01481 717134



## Appendix E – Case studies, extra-care housing and Learning Disabilities

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### Case study 1 – ‘my parents never thought I’d have my own home’

I am a man with mild learning disabilities on the autistic spectrum. For many years I lived at home with my parents, but I struggled to cope, being admitted to residential care in 1999. When I moved into residential care I would avoid all eye contact and cover my face if people tried to talk to me. Over several years living in the home my confidence grew and I became better able to cope with others. I now work 5 days a week at GROW and I love my job. I have lots of friends at work and through my family and the church. When my family saw the new flats in Extra- Care Housing they were really excited about the possibility of me having my own home but never ever thought it could be a reality for me. When we started to talk about a possible move I became quite anxious as I was happy and settled in the residential home. Staff and my family worked really hard to reassure me that this would be a great move for me and although I started to become excited about moving it made me anxious to think about how much would change. My family and staff supported me during the transition and I even needed to take some extra medication for a short time to help me cope with the thought of the move!

BUT ..... over the last year since my move to my new flat I have absolutely thrived. I have made lots of new friends, I visit my neighbours all the time for coffee, and I am now part of the extra- care housing community that includes people I may never have spoken to prior to moving. I feel confident in many aspects of my life now that I may previously have struggled with even when in the residential home. My parents come and have lunch with me on Sunday most weeks now, either in my flat or in the restaurant, and I have a full and interesting life. I still see the staff who supported me in the residential home but only for occasional social outings and the odd health appointment now as I don’t need them to do things for me anymore. I am able to do so much more for myself now I have my own space!

### Case study 2 – ‘the other place? - it’s a mad house!’

If you ask me now about the residential home in which I used to live I will tell you ‘it’s a mad house!’ I am a man in my 60’s and I have lived in hospital or residential care for most of my life. I have a moderate learning disability but I also struggle with my mental health at times. When I lived with others I found it really difficult, the constant noise and activity drove me mad. I would often hallucinate and become very agitated with episodes of mental ill health that often lasted for weeks at a time. I became paranoid or had manic episodes which caused me to present with quite bizarre behaviour and people in the community avoided me.

When staff first talked about a flat I struggled with the thought of a move even though I hated living with others. Staff talked to me about it often but it was only when they told me I could take all the pictures on the wall in my old home with me I was more than happy to move, in fact I started packing up long before my move was due to happen. Staff worked alongside the new staff who would be supporting me and we worked out a way to move me prior to the others to ensure I would be first on the list for a new flat.

When I did move I still had times when my mental health would deteriorate, but never to the extent that it did previously. Some of my new neighbours and some of the new staff who were working with me struggled at first when my mental health was not great but staff who knew me well from my years in residential care continued to work alongside them to support me. Now people know me well in my new home they understand if I am less well mentally and help me through my difficult times, but my episodes are shorter and less intense than they ever were before because I am happy. I have learnt new skills since being in my new home, but I have also needed additional support with other aspects of my care at times, but the two staff teams work well together to support me. I still attend important things like church but have also joined in many new activities offered mixing with people who may not have been friendly with me before.

### Case study 3 – **‘this move has quite literally changed my life’**

I am a young man with Down’s syndrome and I have lived in residential accommodation for some years since I left home. I have struggled to live with others as their untidy habits make me quite anxious so I would constantly tidy my environment. This became such an obsession for me it completely controlled my life, so much so I would refuse all activities in the community to stay home and ensure that everything was in its place. I developed bizarre rituals, some of which became quite dangerous, in a bid to try to control my environment. Staff supporting me knew how difficult this was for me so tried to make the environment easier for me to manage but my obsessions became more and more compulsive. The people I lived with often became cross with me because I would constantly tidy their things away, sometimes in the bin, this would cause them to become agitated and we would often have words which sometimes came to blows!

When the opportunity came along for me to have an assessment for the extra- care housing scheme to see if they could meet my needs, the staff who supported me felt that this was a great opportunity for me. When the assessment was complete the team at extra- care felt that my needs would probably be too great for them to support alone so my application was initially rejected. BUT staff supporting me worked together with the scheme managers to develop a jointly delivered person centred package of care to enable the move to be possible. The extra- care team shadowed staff who knew me well and learned how I liked things done. Both staff teams now work together to coordinate my care with one team generally helping me with domestic activities and the learning disability team ensuring I am supported to develop my daily living skills, attend health appointments, and access the community. My brother and I are very close, he has helped me to make the flat my own, we have been out and shopped for a new settee and lots of pictures and cushions. The move to extra- care housing has quite literally changed my life. I now access the community every day. I still like to tidy my flat but because I live on my own this no longer affects anyone else and when I put things away they stay where I put them!

## Appendix F – Case study on care-coordination and integration

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### Harry and Edith

*Harry (79) and Edith (77) live in an old Guernsey cottage in St Peters where they moved after they got married. Their son (Mark) and daughter (Karen) have both moved to the UK where they are settled and cannot come back frequently.*

#### Scenario one:

In 2010, Harry was admitted to hospital after a fall. When Harry was fit to be discharged he was sent home, but no one enquired about whether Edith would be able to cope looking after him. Since he was struggling with the stairs, Edith arranged to move the bed into the sitting room. Whilst there was a toilet downstairs which Harry could get to with a bit of help, the bathroom was up stairs and Harry was reluctant to attempt to climb them. Harry depended on Edith to help him wash, go out, drive, do the shopping, cook, and do any lifting or carrying.

Whilst Edith had been a regular attender at W.I. meetings and enjoyed playing euchre with friends, she did not like leaving Harry on his own in case he fell again, so increasingly she stopped socialising to care for Harry.

Edith had been feeling stressed, anxious and down, and went to see her GP who gave her anti-depressants and diagnosed her with high blood pressure. Whilst the GP helped with her health, he did not ask how she was coping with caring for Harry.

Earlier this year whilst Edith was out doing the grocery shopping, Harry had another fall. He ended up in hospital again and was no longer able to stand up on his own easily. Harry was discharged home, as Edith was insistent that she could cope with looking after him. However, Edith became unwell and their daughter Karen, who was concerned, flew over to help.

Karen contacted community services for help. When they undertook an assessment they found that Edith was no longer able to go out to the shops or get Harry out of bed, and that caring for him was having a detrimental impact on her health. The house was not suited to adaptations such as hoists, which would help Edith to care for Harry. A social worker assisted in finding a place for Harry at a residential care home and Edith now visits him regularly.

#### Scenario two:

In 2010, Harry was admitted to hospital after a fall. Whilst Harry was in hospital a member of the discharge team undertook a carer's assessment to talk to Edith one-to-one about how she could cope with caring for Harry. It became clear that there would be some difficulties for Edith caring for Harry in their current cottage. After this they met with Edith and Harry to discuss what support she might need to look after him at home. Edith and Harry were offered a short-term placement in an extra care flat with a programme of physiotherapy to help Harry to regain his confidence in moving around the flat. Within the flat, with the aid of some

equipment, he was able to prepare himself basic meals, get out of bed, and shower by himself. He could even go down to the café in the extra care housing complex.

After a week living in an extra care flat, Harry and Edith saw the potential benefit of changing their environment and decided that they may need to consider moving house to somewhere which was more accessible.

Karen came to help Edith with preparations; and the staff at the extra care scheme directed them to a helpful information service, website and booklet which outlined the available options. Staff at the information service talked through the options with them. Since Harry was now mostly self-sufficient, they decided that they didn't yet need to be in an extra care facility permanently and looked instead at sheltered housing. Edith and Harry found an accessible flat in a sheltered housing complex and Karen helped them to move house.

Through the information service they found out about some services that could help them: they had a 'Lifeline' telecare system fitted, so Edith could go out and know that if Harry fell again he would be able to call for help easily; Edith also undertook a course on using an iPad and learnt how to SKYPE Mark and Karen. Edith and Harry knew some of the other people who lived in the sheltered housing complex and they met with them regularly for meals, games and outings. Harry knew that he could ask his neighbours for help if he needed to without having to go outside or tackle any steps.

When Edith was diagnosed with high blood pressure her GP surgery provided her with information on a walking for health group, she was visited by a Health Visitor to help her to plan her diet, and her health started to improve again.

After his physiotherapy Harry remained reasonably active and confident, but he still struggled with going out shopping on his own, and lifting and carrying heavy items. When Edith went down with a bad chest infection the GP came to visit and asked Harry and Edith how they were coping. The GP referred Harry and Edith to community services for some temporary support with shopping, hot meals and getting Edith out of bed in the morning. Edith recovered, and she and Harry were able to remain living in their apartment.

- Fictional illustration inspired by 'Two different stories of caring' from the National Collaboration for Integrated Care and Support (2013) *Integrated Care and Support: Our Shared Commitment* Available at: <https://www.gov.uk/government/publications/integrated-care> [accessed 30/11/15].

## Appendix II: A prioritised action plan for implementing the recommendations of the Supported Living and Ageing Well Strategy

### IMPLEMENTATION PLAN FOR THE SUPPORTED LIVING AND AGEING WELL STRATEGY

|  |  |  |  |
|--|--|--|--|
|  | Anticipated progress with allocation of additional resources as described in Policy Letter (including approval of HSSD and Policy Council Transformation and Transition Fund bids) |  | Anticipated progress using current resources |
|--|--|--|--|

|  | Recommendation | 2016 | 2017 | 2018 | 2019 | Outcome   | Associated timescale  | Key parties   | Resources  |
|--|----------------|------|------|------|------|---|---|---|--|
| Establish and resource a strategic planning function   | 3(a) and 3(b)  |      |      |      |      |   | 12 months to establish function, thereafter business as usual | Policy and Resources Committee, other States Committees, private and third sector organisations | Dependent on allocation of funds from Transformation and Transition Fund |
| To bring forward proposals to increase contribution rates to the Long-term Care Insurance Fund for employed, self-employed and non-employed persons by no less than 0.5% | 7(a)           | *    | *    |      |      | Include proposals as part of the 2016 uprating report to the States | Proposed increase to come into effect on 01.01.17.            | Committee for Employment and Social Security  | Within existing resources  |

|   | Recommendation      | 2016 |  |  |  | 2017 |  |  |   | 2018 |  |  |  | 2019 |  |  |  | Outcome  | Associated timescale   | Key parties  | Resources                 |
|---|---------------------|------|--|--|--|------|--|--|---|------|--|--|--|------|--|--|--|--|--|--|---------------------------|
| Report to the States on the arrangements by which political direction and oversight will be provided to enable SLAWS recommendations to be progressed   | Policy Letter (iii) |      |  |  |  |      |  |  | * |      |  |  |  |      |  |  |  | Report to the States                                   | June 2017 at the earliest - to tie in with the process for prioritising policy | Policy and Resources, Health and Social Care, Employment and Social Security, Environment and Infrastructure Committees, with States of Alderney, third sector groups: | Within existing resources |
| To investigate in detail the implications for contributors, individuals and for the States of the implications of the principle that the Long-term Care Insurance Fund should cover care and support costs only | 7(e)                |      |  |  |  |      |  |  | * |      |  |  |  |      |  |  |  | Report to the States with findings and recommendations | No later than October 2017   | Committee for Employment and Social Security, in conjunction with the Policy and Resources Committee   | Within existing resources |

|  | Recommendation | 2016 |  |  | 2017 |  |  | 2018 |  |  | 2019 |  |  | Outcome  | Associated timescale | Key parties  | Resources  |
|--|----------------|------|--|--|------|--|--|------|--|--|------|--|--|--|----------------------|--|--|
| Further research into the specific needs of Alderney   | 4(a)           |      |  |  |      |  |  |      |  |  |      |  |  | Report to the States   | By the end of 2017   | Policy and Resources Committee, States of Alderney, private and third sector organisations     | Dependent on allocation of funds from Transformation and Transition Fund |
| Review the policies and procedures by which individuals can access long-term care provided in residential and nursing homes and extra care housing | 6(1)           |      |  |  |      |  |  |      |  |  |      |  |  | Report to Policy and Resources Committee with any recommendations for change | By the end of 2017   | Committees for Health and Social Care, Employment and Social Security and Policy and Resources | Dependent on allocation of funds from Transformation and Transition Fund |

|   | Recommendation | 2016 | 2017 | 2018 | 2019 | Outcome | Associated timescale          | Key parties   | Resources  |
|---|----------------|------|------|------|------|---------|-------------------------------|---|--|
| Review, as a matter of priority, the range, provision and funding of short break services for persons with long-term care needs and their carers. Prepare a business case for development/realignment of short break services | 6(b)           |      |      |      |      |         | No later than the end of 2017 | Committees for Health and Social Care and Employment and Social Security and Policy and Resources Committee | Dependent on allocation of funds from Transformation and Transition Fund |
| Investigate, as a matter of priority, the expansion of the range and availability of community care services  | 6(d)           |      |      |      |      |         | No later than the end of 2017 | Committee for Health and Social Care and Policy and Resources Committee                                     | Dependent on allocation of funds from Transformation and Transition Fund |



|  | Recommendation | 2016 |  |  | 2017 |  |  | 2018 |  |  | 2019 |  |  | Outcome                                  | Associated timescale          | Key parties   | Resources  |
|--|----------------|------|--|--|------|--|--|------|--|--|------|--|--|--|-------------------------------|---|--|
|  |                |      |  |  |      |  |  |      |  |  |      |  |  |  |                               |   |  |
| Investigate the establishment of a proactive care coordination service                           | 6(c)           |      |  |  |      |  |  |      |  |  |      |  |  | Report to Policy and Resources Committee | No later than the end of 2017 | Committee for Health and Social Care and Policy and Resources Committee                         | Dependent on allocation of funds from Transformation and Transition Fund |
| Review arrangements for the provision, management and funding of aids, equipment and adaptations | 6(e)           |      |  |  |      |  |  |      |  |  |      |  |  | Report to Policy and Resources Committee | No later than the end of 2017 | Committees for Health and Social Care, Employment and Social Security, and Policy and Resources | Dependent on allocation of funds from Transformation and Transition Fund |

|  | Recommendation | 2016 | 2017 | 2018 | 2019 | Outcome | Associated timescale  | Key parties  | Resources  |
|--|----------------|------|------|------|------|---------|---|--|--|
| Investigate the transfer of landlord responsibilities for specialist accommodation managed by the Committee for Health and Social Care to the Committee for Employment and Social Security | 6(k)           |      |      |      |      |         | Report to Policy and Resources Committee with findings, to include identifying redevelopment costs to provide purpose-built accommodation | Committees for Health and Social Care, Employment and Social Security, and Policy and Resources                              | Within existing resources  |
| Develop, as a matter of priority, a Carers Strategy  | 6(a)           |      |      |      |      |         | Report to the States  | Policy and Resources, Health and Social Care, and Employment and Social Security Committees, appropriate third sector groups | Dependent on allocation of funds from Transformation and Transition Fund |

|   | Recom<br>mendati<br>on | 2016 | 2017 | 2018 | 2019 | Outcome   | Associated<br>timescale    | Key parties  | Resources                         |
|---|------------------------|------|------|------|------|---|----------------------------|--|-----------------------------------|
| To direct that progress on implementing the actions in the Strategy form part of the annual reporting on the Policy and Resource Plan that will commence in June 2018.  | Policy Letter (vii)    |      |      | *    |      | Report to the States  | June 2018                  | To be determined   | Within existing resources         |
| To investigate in detail the implications for contributors, individuals and for the States of the application of the principle that the Long-term Care Insurance Scheme should be extended to cover the cost of care and support at home. This should include: a reviewing role of related benefits (SDB & Carer's Allowance); and detailed investigation into personal budgets | 7(i) and 7(j)          |      |      | *    |      | Report to the States with details of findings and recommendations | No later than October 2018 | Committee for Employment and Social Security, in conjunction with the Policy and Resources Committee | Will require additional resources |

|  | Recommendation | 2016 |  |  | 2017 |  |  | 2018 |  |   | 2019 |  |  | Outcome                                  | Associated timescale          | Key parties   | Resources  |
|--|----------------|------|--|--|------|--|--|------|--|---|------|--|--|--|-------------------------------|---|--|
| Investigate the introduction of 'telecare', including (if appropriate) commissioning a pilot project to assist with the research | 6(f)           |      |  |  |      |  |  |      |  | * |      |  |  | Report to Policy and Resources Committee | No later than the end of 2018 | Committee for Health and Social Care and Policy and Resources Committee | Dependent on allocation of funds from Transformation and Transition Fund |
| Investigate the impact of ageing in Guernsey and Alderney  | 5(a)           |      |  |  |      |  |  |      |  |   |      |  |  | Report to the States                     | No later than February 2019.  | Policy and Resources Committee  | Dependent on allocation of funds from Transformation and Transition Fund |
| Investigate the issue of loneliness in Guernsey and Alderney   | 5(b)           |      |  |  |      |  |  |      |  |   |      |  |  | Report to the States                     | Ongoing                       | Policy and Resources Committee  | Dependent on allocation of funds from Transformation and Transition Fund |

|   | Recommendation | 2016 | 2017 | 2018 | 2019 | Outcome   | Associated timescale      | Key parties   | Resources   |
|---|----------------|------|------|------|------|---|---------------------------|---|---|
| Monitor and support initiatives that engender a positive, enabling and person-centred attitude towards the delivery of care and support   | 5(c)           |      |      |      |      |   | Ongoing                   | Policy and Resources Committee  | Dependent on allocation of funds from Transformation and Transition Fund          |
|   |                |      |      |      |      |   |                           |   |   |
|   |                |      |      |      |      |   |                           |   |   |
| As part of the Disability and Inclusion Strategy, to develop condition specific frameworks for dementia, autism and learning disabilities, as to identify gaps in service provision | 6(g) and 6(h)  |      |      |      |      | Report to Policy and Resources Committee with recommendations to address gaps | Timescale to be confirmed | Committee for Health and Social Care and Policy and Resources Committee | To be taken forward from resources allocated to Disability and Inclusion Strategy |
|   |                |      |      |      |      |   |                           |   |   |
|   |                |      |      |      |      |   |                           |   |   |

|  | Recommendation | 2016 | 2017 | 2018 | 2019 | Outcome   | Associated timescale      | Key parties   | Resources  |
|--|----------------|------|------|------|------|---|---------------------------|---|--|
| As part of the Mental Health and Wellbeing Strategy to identify priorities for support and service development needed by people with enduring mental health conditions | 6(i)           |      |      |      |      |   |                           | Committee for Health and Social Care, working with the third sector, and Policy and Resources Committee | To be taken forward from resources allocated to Mental Health and Wellbeing Strategy |
|  |                |      |      |      |      | Report priorities to Policy and Resources Committee | Timescale to be confirmed |   |  |

|  | Recommendation    | 2016 | 2017 | 2018 | 2019 | Outcome | Associated timescale | Key parties  | Resources  |
|--|-------------------|------|------|------|------|---------|----------------------|--|--|
| Keep under review whether there is a strategic, long-term financial need to introduce: (i) the inclusion of capital assets in any means-testing of benefits associated with the provision of long-term care; and (ii) the capping of care costs to set out the respective funding liabilities for individuals and for the States | 7(l)              |      |      |      |      |         | Ongoing              | Committee for Employment and Social Security   | Within existing resources  |
|  |                   |      |      |      |      |         |                      |  |  |
|  |                   |      |      |      |      |         |                      |  |  |
| To acknowledge that to bring about the level of transformation change will require further research and other implementation activities that can only be undertaken successfully by applying to them programme and project management disciplines and by assigning to them the right level of appropriately skilled resources    | Policy Letter (v) |      |      |      |      |         | Ongoing              | Policy and Resources and Health and Social Care Committees, other States Committees, private/third sector partners | This will depend on Policy Council's bid from the Transformation and Transition Fund |
|  |                   |      |      |      |      |         |                      |  |  |
|  |                   |      |      |      |      |         |                      |  |  |

### **Appendix III**

#### **A summary of the recommendations of the Working Party's research report**

Recommendation (i) of this Policy Letter asks the States to approve all of the Working Party's recommendations to progress the Supported Living and Ageing Well Strategy.

These recommendations are reproduced below:

- 1a) To endorse the strategic framework for the Supported Living and Ageing Well Strategy.

#### **3     *Establishing a strategic planning function (Section 3 of the research report)***

- 3a) To agree to establish and resource a function to plan strategically to meet the long-term care and support needs of the populations of Guernsey and Alderney.

- 3b) To note that specifically this States' strategic planning function will:

- (i) include development of the capability routinely to model and project future:
  - levels of need;
  - costs of care and support services; and
  - workforce implications;
- (ii) work in partnership with the private and third sectors in each island to focus on facilitating the development of cooperative relationships within the wider community of providers and funders, and to commission and facilitate the development of services within the private and third sectors to complement those provided by the States;
- (iii) investigate, in conjunction with the Committee for Employment and Social Security, the introduction of service level agreements with providers of care and support services specifying the quality standards expected where significant funding is being provided either directly or indirectly by the States.

#### **4.     *Meeting care and support needs in Alderney (Section 4 of the research report)***

- 4a) To direct the Policy and Resources Committee to carry out research into the specific needs and requirements in Alderney, with a view to a report on any modifications of the Strategy for Alderney being presented to the States by the end of 2017.



**5. *Societal issues affecting the SLAWS (Section 5 of the research report)***

- 5a) To direct the Policy and Resources Committee to investigate the impact of ageism in Guernsey and Alderney and how it could be addressed reporting to the States with its findings and any recommendations no later than February 2019.
- 5b) To direct the Policy and Resources Committee to monitor and support initiatives within Guernsey and Alderney that engender a positive, enabling and person-centred attitude towards the delivery of support and care.
- 5c) To direct the Policy and Resources Committee to investigate the issue of loneliness in Guernsey and Alderney, reporting to the States with its findings and any recommendations no later than February 2019.

**6. *Service development priorities (Section 6 of the research report)***

- 6a) To direct the Policy and Resources Committee, in conjunction with the Committees for Health and Social Care and Employment and Social Security, and appropriate third sector organisations, to develop, as a matter of priority, a Carers Strategy and to report to the States with its recommendations no later than June 2018.
- 6b) To direct the Committees for Health and Social Care, and Employment and Social Security to review and address, as a matter of priority, the range, provision and funding of short break services for both persons with long-term care needs and their carers, and to report to the Policy and Resources Committee no later than the end of 2017 with a business case for the development and realignment of short break services, in the light of their findings.
- 6c) To direct the Committee for Health and Social Care to report to the Policy and Resources Committee no later than the end of 2017, with the results of an investigation into the establishment of a proactive care coordination service, providing a single point of contact to those with significant care and support needs to assist them in arranging and coordinating their care and support from public, private and third sector bodies, including signposting to advice on how services are funded and paid for.
- 6d) To direct the Committee for Health and Social Care to investigate, as a matter of priority, the expansion of the range and availability of community care services, including but not limited to:
  - (i) the expansion of services for rehabilitation and re-ablement for those recovering from hospitalisation;
  - (ii) the establishment of short-term care in the community to provide an intermediate level of support between hospital and living at home;

- and to report to the Policy and Resources Committee no later than the end of 2017 with the relevant a business case(s), in the light of their findings.
- 6e) To direct the Committees for Health and Social Care, and Employment and Social Security to review the arrangements for the provision, management and funding of aids, equipment and adaptations, and to report to the Policy and Resources Committee no later than the end of 2017 with their findings.
  - 6f) To direct the Committee for Health and Social Care to investigate the introduction of ‘telecare’ including, if appropriate, commissioning a pilot project to assist with this research, and to report to the Policy and Resources Committee no later than the end of 2017 with its findings.
  - 6g) To note that as part of the Disability and Inclusion Strategy, the Committee for Health and Social Care will be developing condition-specific frameworks for dementia, autism and learning disabilities.
  - 6h) To direct the Committee for Health and Social Care that, as part of the development of these frameworks, it should seek to identify gaps in service provision and to report these to the Policy and Resources Committee with its recommendations on how these should be addressed.
  - 6i) To direct the Committee for Health and Social Care that, as part of the development of the Mental Health and Wellbeing Strategy for which it is responsible, it should identify the priorities for support and service development needed by people with enduring mental health conditions and to report these to the Policy and Resources Committee.
  - 6j) To direct that, as part of their strategic planning, the Committees for Health and Social Care, Employment and Social Security, and Environment and Infrastructure, should take account of the importance of the provision of specialist housing to meet the long-term care needs of persons with various impairments and conditions.
  - 6k) To direct the Committees for Health and Social Care, and Employment and Social Security to investigate the transfer of landlord responsibilities for specialist accommodation managed by the former Committee to the latter Committee, and to report to the Policy and Resources Committee no later than the end of 2017 with their findings, including the identification of any consequent redevelopment costs to provide purpose-built accommodation which will require a financial contribution from the States Corporate Housing Programme Fund.
  - 6l) To direct the Committees for Health and Social Care, and Employment and Social Security, to review the policies and procedures by which individuals can access long-term care provided in residential and nursing homes and extra care housing, and to report to the Policy and Resources Committee with any recommendations for change by the end of 2017.

7. *Address strategic funding issues (Section 7 of the research report)*

- 7a) To direct the Committee for Employment and Social Security to increase contribution rates to the Long-term Care Insurance Fund for employed, self-employed and non-employed persons by no less than 0.5% from 1<sup>st</sup> January 2017;
- 7b) To agree, in principle, that wherever care and support is received, for accounting and charging purposes, the costs associated with the provision of long-term care services should be separated into three distinct areas: accommodation; day- to-day living expenses; and care and support;
- 7c) To agree, in principle, that the Long-term Care Insurance Fund should be used to meet the costs of care and support only, with payments for accommodation costs and living expenses being the responsibility of the individual receiving care and support.
- 7d) To agree, in principle, that where an individual receiving long-term care was unable to meet their accommodation and living costs in full, they would be eligible for means-tested assistance via Supplementary Benefit.
- 7e) To direct the Committee for Employment and Social Security, in conjunction with the Policy and Resources Committee, to investigate in detail the implications for contributors, individuals and for the States of the application of the principle that the Long-term Care Insurance Fund should cover care and support costs only, and to report to the States with its findings and recommendations no later than October 2017.
- 7f) To agree that investigation of this principle shall be limited, in the first stage, to the implications related to care and support provided to individuals in public and private sector residential and nursing homes.
- 7g) To note that any costs associated with the investigation of this principle will be met from the Long-term Care Insurance Fund.
- 7h) To agree, in principle, that the Long-term Care Insurance Scheme should be extended to cover care and support costs for people living in their own homes (including those accommodated in their own homes in sheltered and extra care housing).
- 7i) To direct the Committee for Employment and Social Security, in conjunction with the Policy and Resources Committee, to investigate in detail the implications for contributors, individuals and for the States of the application of the principle that the Long-term Care Insurance Scheme should be extended to cover the cost of care and support at home, and to report to the States with its findings and recommendations no later than October 2018.
- 7j) To agree that the investigation of this principle should include:

- a review of the role of related benefits such as Severe Disability Benefit and Carer's Allowance; and
  - detailed investigation into the possibility of introducing personal budgets, including, if appropriate, the establishment of a pilot project to inform the research.
- 7k) To note that any costs associated with the investigation of this principle will be met from the Long-term Care Insurance Fund.
- 7l) To direct the Committee for Employment and Social Security to keep under review whether there is a strategic, long-term financial need to introduce: (i) the inclusion of capital assets in any means-testing of benefits associated with the provision of long-term care; and (ii) the capping of care costs to set out the respective funding liabilities for individuals and for the States.

**(N.B. The Treasury and Resources Department notes the considerable efforts that have been undertaken by the SLAWS Working Party in order to address the long-term issues related to supported living and ageing well in the context of the challenging demographic changes that Guernsey is facing.**

**With regards to the establishment of a strategic planning function it is expected that any resource implications will be funded through a reallocation of existing resources (i.e. by reducing some current services which are considered to be of lower priority, including reviewing the skills, competences and duties of existing staff members) or prioritised for additional budget generated through realisation of a reform dividend.**

**As social policy development was one of the areas prioritised by the States as part of the 2016 Budget Report, funding requests for temporary resources related to strategic planning, including the many areas of review and research highlighted in sections 4 – 6 of Appendix III, could potentially be made via the Transformation and Transition Fund in order to support the development and delivery of the strategy, with all applications being made in full accordance with the fund application rulebook.**

**The Treasury and Resources Department acknowledges that to support the strategy changes to the Long-term Care Insurance Fund may be required. However, it is concerned that the proposal in section 7 of Appendix III, to increase contribution levels by 0.5% from January 2017, could remove the urgency or perceived need to take further action and therefore make additional changes in support of the strategy more difficult to achieve.**

**The Board is of the view that the long-term challenges the strategy highlights are best addressed by way of a package of measures to be considered by the States, rather than measures in succession as is proposed, and that the utilisation of the Long-term Care Insurance Fund should be clarified in accordance with the package of measures.**

**In relation to the nine guiding principles of the strategy, which are listed in section 9 of the report, it is expected that a strategic focus on service prioritisation and the generation of a reform dividend is maintained through all stages of the development and delivery of the strategy.)**

The States are asked to decide:-

XIV.- Whether, after consideration of the Policy Letter dated 7<sup>th</sup> December, 2015, of the Policy Council, they are of the opinion:-

1. To endorse all of the recommendations to progress the Supported Living and Ageing Well Strategy, as set out in the Working Party's research report and reproduced in Appendix III of that Policy Letter.

2. To direct that, until alternative arrangements are agreed, the Policy Council, and thereafter the Policy and Resources Committee, shall be responsible for ensuring that the Supported Living and Ageing Well Strategy continues to be taken forward.
3. To direct the Policy and Resources Committee, as part of its finalisation of the Policy and Resource Plan, to report to the States of Deliberation, no later than June 2017, on the arrangements by which political direction and oversight will be provided to enable the Working Party's recommendations to be progressed and implemented, having first consulted with the Committees for Health and Social Care, Employment and Social Security, and Environment and Infrastructure, together with the States of Alderney and appropriate third sector groups.
4. To approve, in principle, the implementation plan and timescales associated with taking forward the various elements of the Supported Living and Ageing Well Strategy, as shown in Appendix II of that Policy Letter, but to ask the Policy and Resources Committee to bring forward firm proposals as part of the aforementioned Policy and Resource Plan, including identification of the resources required.
5. To acknowledge that to bring about the level of transformational change identified by the investigations undertaken to date will require significant further research and other implementation activities, which can only be undertaken successfully by applying to them programme and project management disciplines, and by assigning to them the right level of appropriately skilled resources.
6. To make the nine strategic commitments required to bring about the significant transformational change necessary to deliver the Supported Living and Ageing Well Strategy.
7. To direct that progress on implementing the actions in the Supported Living and Ageing Well Strategy form part of the annual reporting on the Policy and Resource Plan that will commence in June 2018.