Initial Report for the Supported Living and Ageing Well Strategy (SLAWS) Working Party

A New Health and Social Care System

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The report was produced by an independent consultant, Melinda Phillips for the Policy Council's Supported Living and Ageing Well Strategy (SLAWS) Working Party. The views expressed in this document are the views of Melinda Phillips informed by the evidence she gathered in August 2014. They do not necessarily represent the views of the SLAWS Working Party or the States of Guernsey.

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Executive Summary

The brief

This report is the diagnostic stage of the work commissioned by the SLAWS Working Party to provide a strategic framework to:

- Promote, improve and protect individual's health, wellbeing and dignity.
- Ensure there are opportunities for independence and choice.
- Enable fair access to appropriate care and support and suitable housing.
- 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.
- Have regard to affordability and financial viability for the funders, providers and recipients of care and support services.
- Ensure the service provision and funding options are sustainable in the medium and long term.
- Ensure safe, quality care and ensure standards through appropriate regulation.

Through the articulation of a framework SLAWS intends to answer the specific questions:

What care and support accommodation services are needed?

Who should provide them?

How should they be paid for?

The guiding vision is the 20:20 vision[1], which states that by 2020, the groundwork will be laid to enable all islanders to lead healthy, independent lives.

The need for change

The Guernsey health and social care system, like that of most advanced economies, is simply trying to catch up with what society now looks like. In Guernsey and elsewhere health systems have focused on treating disease and responding to crisis through hospitals and institutions, other services have developed on a piecemeal basis in response to perceived needs.

[1] HSSD (2011) "Future 2020 Vision of Health and Social Services Systems" in *Billet d'État VIII, May 2011* and Policy Council (2013) "2020 Vision: Progress Report and Next Steps" in *Billet d'État I, January 2013* Available at: http://www.gov.gg/Hssd2020Vision

Systems that were set up to treat one illness at a time now find that they can no longer address the needs of people who often have complex multiple conditions. 1 in 3 of our older people, for example, who have physical problems will also have mental health issues so support involves several services at the same time.

Huge progress has been made in reducing premature deaths from such things as strokes, cancer and heart diseases and many people are living longer with these conditions. So managing long-term conditions is a good illustration of the way the system no longer responds to the needs of the population. For Guernsey, and all advanced economies, the question is: should these years be in hospitals and care homes or should the system change so that it is spent at home with more self-management.

Another example is young people who once would not have reached adulthood also live long adult lives and they want more independence and more choices of how to live their lives supported by the system.

Society has indeed changed – demographics, technological advances and changed expectations means that we need to look at how the whole system works for people.

At the heart of the debate is the need to make the overall system more person centred and that requires significant coordination across services to deliver what people need, when they need it and where they need it.

A hospital-based model is also expensive and unsustainable in the face of increased demand and longevity. Guernsey has to consider how it moves towards a culture of more self-management backed by support services at home and reducing hospital and premature institutional care.

The approach

During this diagnostic stage of the work, I have consulted widely with service users and professionals about what works and does not work for them. I have asked people about their experiences of using the services. I have identified the big issues that get in the way of person centred coordinated care and have suggested how they should change. I have looked at how other countries have faced similar issues.

Rather than look at individual services, which will not necessarily deliver person centred care, I have looked at the components of care or the collection of services and approaches that people need to live well at different times of their lives.

For each component of care I have suggested good practice and compared the position in Guernsey and backed that up with comments and views from the consultations. It is no

coincidence that the same big issues are a blockage to delivering high quality coordinated care whichever component one looks at.

The 8 components of care[2] I have looked at and talked to people about are

- Support to healthy, active ageing and independence
- Support to live well with simple or stable long-term conditions at home.
- Support to live well with complex co- morbidities, dementia and frailty, both at home and in a home.
- Rapid support close to home in time of crisis
- Good hospital and specialist care when needed
- Good discharge planning and post discharge support and good rehabilitation and re-ablement after acute illness or injury
- High quality nursing and residential care and other forms of supported accommodation for those who need it
- Choice, control and support towards the end of life

The report is structured in eight sections

- **Section one** is the brief.
- **Section two** outlines my approach and what I have done.
- **Section three** explains why Guernsey in common with other Western countries needs to make substantial changes to the health and social care system.
- **Section four** describes what an integrated system might look like. It explains what components of care I have used to test the Guernsey system and why. Components of care are the multiple services people need at the same time to support them at different points of their lives.
- **Section five** covers the big themes that emerge from this work.
- **Section six** provides the bulk of the back up evidence from the consultation exercise. It goes through each component of care giving best practices and comparing Guernsey's position to this. It also provides direct quotes and comments made by users and providers during the exercise.
- **Section seven** offers conclusions and next steps
- **Section eight** includes the appendices

[2] Based on the Kings Fund (2014) "Making our health and care systems fit for an ageing population". Available at: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf

The findings

There are 7 big themes and 4 specific gaps in services that emerge from this work which are discussed in detail in section 5.

1. There is a need to develop the planning role of the state. There also needs to have clarity about the role of the States as a provider. Which services should it provide itself and which outsource? As a consequence of this lack of clarity, the roles of the third sector and the private sector are unclear and under developed.
2. There is a need to systematically collect and analyse data in order to plan services.
3. The GP service must be reconnected to the rest of health and social care as it is so critical to the rest of the system working well for people.
4. Islanders should have the choice to have care at home/in a supported living option or in a home. There should be a rebalancing of services in institutional and hospital care and community care. This will require a substantial development of social care services to support people at home.
5. There is an overall lack of coordination of services, which needs to be addressed.
6. There is a need to put mental health services, particularly dementia care, on a par with physical health services and ensure there is a strong connection between the two. (Roughly a third of people with physical conditions also have a mental health condition in the UK and although there is no statistic in Guernsey on this, it is likely that the figure will be similar).
7. Relationships with and capacity of the third sector and the private sector need to be developed as part of the States strategic planning role.

There are also some very specific gaps in the overall service which are also clearly illustrated in section 6 which are:

1. The need to invest in carers and understand and address their needs as well as the needs of the people they care for.
2. The need to develop adult mental health and dementia services.
3. The need to increase respite care provisions.
4. The need to provide more accommodation with care options either directly or through partnerships with the private and third sectors.

Guernsey is, therefore, at a crossroads. It can either continue with a medical and hospital centric system which will cost more and more as it has to cope with larger numbers of older people in particular (80% of the health and care budget go on older people), or it can make the shift to more care at home supported by coordinated community services including the GP service. Barriers between primary and secondary care and private and public parts of the system and around physical and mental health needs will have to be overcome. Changes also have to be supported by an emphasis on healthy living and taking the public health responsibilities seriously whether that's tackling obesity, health inequalities or drug and alcohol abuse.

There are opportunities to make changes, which will not arise again for some time. These include new licences for GPs, the renegotiation of the contracts for Physiotherapy and secondary care (MSG) in 2017. Substantial regulatory changes will soon be proposed for implementation over the next few years.

The recommendations

I am mindful of the fact that Guernsey will not get there in one go but if the direction and framework is clear then it is possible to make incremental changes that will not create unintended new barriers. So there can be quick wins too and I am recommending the following approach:

- The States carry out a consultation exercise about the big changes that are being recommended if the vision is agreed. This would consist of a summary of the vision and a structured set of questions.
- Use experts by experience, i.e. service users, to comment on how the care components would work for them.
- Begin the corporate process of developing a robust programme of information gathering and information analysis to assess the need for services for the future. This should be managed corporately so that it takes account of the whole system and not just departmental needs. How GPs are to provide information will have to be decided.
- Produce a project plan for developing community care services, which shifts resources from secondary to primary budgets. Approaches might include reviewing the use of the long-term care fund for care at home (at least in the short term to provide the change management resources), using the voluntary sector to provide the low level services, up-skilling the HSSD care staff to provide more intense care packages backed by specialist nurses working in the community, means testing care fairly across the board and stimulating private sector provision. Shifting the balance between institutional care and hospitals would not provide savings overnight and

some ring fenced funding would be needed to make the changes, but savings could be expected thereafter.

- Proceed with quick wins.

Quick wins or low cost changes

- Undoubtedly, the most popular with relatively modest cost implications would be respite care and carers support.
- Invest in good commissioning skills.
- Invest in developing strategic partnerships and stimulating the third sector service provider market.
- Investigate strategic partnerships with the private and third sectors to provide new accommodation and services with minimal or no grant funding.
- Several mentions were made about the need to finally sort out the equipment store.
- Continue with the plans for regulation ensuring that regulatory developments understand the care and support framework being put in place
- Initiate service level agreements with care homes with clear outcome measures and open up a dialogue with them about providing higher levels of care to people with challenging behaviours.

Finally, whilst there is insufficient data routinely collected in Guernsey to properly analyse future need and provision, I have tried to make some progress towards addressing the three questions.

A New Health and Social Care System

Introduction

This is the diagnostic stage of the work and this report outlines what I have done together with my key findings and recommendations for next steps. If the SLAWS Working Party is in agreement with the way forward the work can be developed as outlined in the recommendations in section 7. The diagnostic work does point to the need for a big sea change in the way that the health and social care system works in Guernsey.

The report is laid out in sections for ease of reading.

Section one is the brief.
Section two outlines my approach and what I have done.
Section three explains why Guernsey in common with other Western countries needs to make substantial changes to the health and social care system.
Section four describes what an integrated system might look like. It explains what components of care I have used to test the Guernsey system and why. Components of care are the multiple services people need at the same time to support them at different points of their lives.
Section five covers the big themes that emerge from this work.
Section six provides the bulk of the back up evidence from the consultation exercise. It goes through each component of care giving best practices and comparing Guernsey's position to this. It also provides direct quotes and comments made by users and providers during the exercise.
Section seven offers conclusions and next steps.
Section eight includes the appendices.

Section one: The brief

To assist Guernsey to articulate a vision of a health and social care system that takes account of the changes in society and responds to the needs of the people of Guernsey for the foreseeable future.

Through this articulation of a vision of what a coordinated service might look like to answer the specific questions posed by SLAWS.

1. What care and support accommodation services are needed?
2. Who should provide them?
3. How should they be paid for?

The objectives of SLAWS

- Reduce where possible the incidence of adults having enduring care and support or supported accommodation needs.
- Improve outcomes for all adults with an enduring care support or supported accommodation needs.
- Protect the health and well-being of the carers of those with care and support needs.

Principles of SLAWS

To provide a strategic framework to:

- Promote, improve and protect individual's health, wellbeing and dignity.
- Ensure there are opportunities for independence and choice.
- Enable fair access to appropriate care and support and suitable housing.
- 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.
- Have regard to affordability and financial viability for the funders, providers and recipients of care and support services.
- Ensure the service provision and funding options are sustainable in the medium and long term.
- Ensure safe, quality care and ensure standards through appropriate regulation.

The guiding vision is the 20:20 vision, which states that by 2020, the groundwork will be laid to enable all islanders to lead healthy, independent lives. This was unanimously confirmed in May 2011 and again in the review carried out in November 2012.

In debating the first 20:20 Vision, the States agreed that there should be three core elements to HSSD's work:

Promoting good health and wellbeing across the community.

Improving outcomes for people who use health and social care services.

Protecting people through high-quality, well-regulated services.

The 20:20 vision emphasises a strategic planned response to long-term challenges, and although there has been considerable work carried out since then there has been no articulation of what an overall strategic health and social care framework might look like so each piece of work sets its own framework.

Most service reviews and service strategies have been system led and not people or needs led. This will continue until an overarching framework is articulated and agreed by Guernsey people, and then changes can fit into the framework without creating unintended barriers or difficulties.

The framework will not be achieved in one go but it can guide changes large and small so that everything moves in the same direction and effort is efficiently targeted.

Section two: My approach and what I have done

I have: -

1. Reviewed Guernsey literature and recent relevant publications from the UK and elsewhere.
2. Talked and consulted widely.
3. Proposed an overarching framework based upon a person centred approach identifying components of care that we might need through our lives.
4. Discussed what areas of the current system need to change in order to move towards person centred health and social care and why.
5. Suggested both short term and longer-term next steps.

What I have not done is to state what is needed, how much and where, as there is little data immediately available in the States to be able to do this. I have, however, given some preliminary thoughts in section seven on each of these three questions but predicated upon a shift towards community provision of which supported accommodation is a part.

The health and social care framework I propose is not age specific although there are inevitable differences in the way that services or components of care need to provide to people of different ages within it.

I am mindful of the many comments, which urge caution and the need to have good planning data to inform decision-making. The States must not base a system that will last for at least the next 20 year, on anecdotes. That requires the planning role of the States to be prioritised.

I am not proposing a model based upon the UK system. There are many advantages to the Guernsey model and a mix of public and private provision works well if it is truly part of an integrated system.

I am not advocating that all care is at home or in extra care, as some people may have feared. There is a clear need for residential and nursing care but it must be a balanced provision which allows choice to individuals to have care at home up to a threshold of need and care in a home as well as a range of options in between.

Rather than look at different services available in Guernsey, I have looked at components of care in section 6 and tested these against what is available in Guernsey. These are the things we need at different points in our lives. The reason for doing this is that we no longer need just single services and if the system is to work around people then it must be able to deliver multiple services at the same time. The real test of any modern service is the way it delivers what we need, when we need it and in the way we need it.

Section three: Why the need for substantial change?

The Guernsey health and social care system, like that of most advanced economies, is simply trying to catch up with what society now looks like.

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 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. Illnesses that previously caused early deaths such as cancer, heart disease and strokes are now being treated successfully. Young people who previously would not have reached adulthood are now living long adult lives. Not only can the system no longer afford to keep people in hospitals or care homes given the increasing numbers and length of time, but it is not how people want to live long periods of their lives.

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.

Since the system in Guernsey has focused on treating disease and responding to crisis through hospitals and institutions, other services have developed on a piecemeal basis in response to perceived needs. There is now a requirement to look at the whole system and how it works around people, to supports the right needs in the right way and importantly how the entire system works together as a whole.

Guernsey is, therefore, at a crossroads. It can either continue with a medical and hospital centric system where costs will continue to rise as it has to cope with larger numbers of older people in particular, or it can make the shift to more self-care at home or in supported living accommodation supported by coordinated community services including the GP service.

Barriers between primary and secondary care and private and public parts of the system and around physical and mental health needs will have to be overcome.

The changes also have to be supported by an emphasis on healthy living through public health policies to tackle such things as loneliness and isolation, obesity, health inequalities and drug and alcohol abuse.

There are opportunities to make changes, which will not arise again for some time. These include the General Medical Practitioners (GMC) revalidation of GPs, which will need to have a new legal framework in place. (This was part of a recent presentation to SLAWS). There will be a renegotiation of the contracts for physiotherapy and secondary care (MSG) in 2017. Substantial regulatory changes planned over the next few years will include regulation of domiciliary care and nursing agency services, followed by extra care and care services provided by HSSD. New regulations will only support the overall health and social care system if it understands what the framework will look like.

There are also consequences of not making the big changes, which include the system becoming more costly and increased criticism of the lack of the personal and co-ordinated service that people want and need. The issues are already clear to many islanders, as the consultation responses have demonstrated.

It is no surprise that in looking at the components of care, the same issues and deficiencies are identified by people in Guernsey whether recipients or deliverers of health and social care. The repetition of these issues illustrate just how these big themes impact on all parts of the system and on peoples quality of life.

The big themes emerging from the work conducted to date are: -

1. There is a need to develop the planning role of the state. There also needs to be clarity about the role of the States as a provider. Which services should it provide itself and which outsource? As a consequence of this lack of clarity, the roles of the third sector and the private sector are unclear and under developed.

2. There is a need to systematically collect and analyse data in order to plan services.

3. The GP service must be reconnected to the rest of health and social care as it is so critical to the rest of the system working well for people.

4. Islanders should have the choice to have care at home/in supported living option or in a home. There should be a rebalancing of services in institutional and hospital care and community care. This will require a substantial development of social care services to support people at home.

5. There is an overall lack of coordination of services, which needs to be addressed.

6. There is a need to put mental health services particularly dementia care on a par with physical health services and ensure there is a strong connection between the two. (Roughly a third of people with physical conditions also have a mental health condition in the UK and although there is no statistic in Guernsey on this, it is likely that the figure will be similar).

7. Relationships with and capacity of the third sector and the private sector need to be developed as part of the States strategic planning role.

There are also some very specific gaps in the overall service which are also clearly illustrated in section 6.

These include:

1. The need to invest in carers and understand and address their needs as well as the needs of the people they care for.

2. The need to develop adult mental health and dementia services.

3. The need to increase respite care provision.

4. The need to provide more accommodation with care options either directly or through partnerships with the private and third sectors.

These themes are developed in section 5 and backed by analysis and quotes from the consultations in section 6.

Section four:
A vision for an integrated framework: What would it look like?

The new framework must be: -

- Integrated to provide person centred coordinated care.
- Provide choices.

Components of care

Rather than look at individual services, which will not necessarily deliver person centred care, we should look at the components of care or the collection of things, that people need to live well at different times of their lives. These components of care should be regularly "walked through" by users and providers to ensure they continue to offer what people need.

The main components of care[3] are:

1. Support to healthy, active ageing and independence.
2. Support to live well with simple or stable long-term conditions at home.
3. Support to live well with complex co- morbidities (see definition in appendix one), dementia and frailty, both at home and in a home.
4. Rapid support close to home in time of crisis and good rehabilitation and re-ablement after acute illness or injury.
5. Good hospital and specialist care when needed.
6. Good discharge planning and post discharge support.
7. High quality nursing and residential care and other forms of supported accommodation for those who need it.
8. Choice, control and support towards the end of life.

The foundation

A modern health and social care system needs a primary care foundation. This is the basic building block of the system. It will look after the health of the community and provide the on-going coordinated care people need as they live longer with multiple conditions or previously life limiting conditions.

[3] Based on the Kings Fund (2014) "Making our health and care systems fit for an ageing population". Available at: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf

It will also help people navigate through services that can provide them with the best quality of life.

Increasingly it is the GP service that fits this requirement in many Western societies. The GP knows the person and often the whole family whether patient or carer. They are trusted and people go to them for advice and guidance. They have information and can influence how we lead healthy lives. They can spot signs of early deterioration so that preventative action can be taken. They should understand the system and can signpost us to what we need and monitor our progress when we return home from an acute incident.

An important role is acting as the patient's advocate. Since primary care practitioners often care for people over extended periods of time, the relationship between patient and doctor is particularly important. Primary health care involves providing treatment for common illnesses, the management of long term illnesses such as diabetes and heart disease and the prevention of future ill-health through advice, immunization and screening programmes.

Choices of care services

When we need care there will be choices for us. The financial system will not discriminate between care at home and care in a home.

Single assessments

There will be a single assessment, which can be shared by professionals across services, rather than multiple assessments carried out by different parts of the health and social care system. This has been achieved in the UK and elsewhere.

Continuity of services

There will be continuity between hospital and home with services following the person. For example nurse specialists such as stroke coordinators and physiotherapists will work with people their own homes not just in hospital and outpatient clinics.

Mental health should be on an equal footing with physical health

All services will take account of mental health needs as well as the physical needs of the individual. Specialist mental health services will be available for all ages. All care providers will be trained in mental health issues.

Carers

Carers will be given their own assessment and their needs taken account of. They will be part of care planning. Social workers drawing up care plans will include a plan to support carers. There will be services such as respite and advocacy to support them to continue caring.

The third sector and private sector

The third sector and private sector will both be clear about their roles within the overall system. There will be opportunities to tender for services and where organisations offer voluntary support they will be treated as partners with clear pathways to access their support.

The States

The States will prioritise its strategic planning role both collecting and analysing data on population, services and performance. It will be able to plan what is needed, when needed and where needed. It will be an expert in commissioning services. (See the definition of expert commissioning in appendix one). It will be the centre of service coordination making sure the parts of the health and social care system works well together. Where it is a provider of service, it will use its expertise to focus on acute services and partner with voluntary organisations to provide low level services.

Information

The States will also ensure that there is good quality, regularly updated information available to the population. It will involve users in making sure that it is clear and helpful.

End of life care

End of life care is part of the cycle of care. Terminal care is no longer defined as care for the last few months or weeks and it can last for several years. Social care staff provide end of life care support through the palliative team. As far as possible we need to provide services to people to die where they choose. At the moment 1 in 2 Guernsey people die in hospital[4] often contrary to their wishes.

Safety and quality

There will be a safe but fair regulatory system. It will cover all services irrespective of who delivers them or where they are delivered. Regulation will support the framework of health and social care including personal budgets where people choose to take an allowance and buy in their own care. It should support rather than impede service delivery and not limit choices people might make including the choice to take some risks.

[4] HSSD (2014) "Health Profile Guernsey 2010-2012". Available at: http://www.gov.gg/publichealth

Integration

Services and approaches will be integrated and focus on the person because they are managed as one overall system with a shared vision and values and clear outcomes for the individual.

Section five: The big themes.

Guernsey benefits from health and social care being a combined department and budget, but there are many disconnects within the system that must be addressed. There are quick wins too as suggested in section 7.

Some of the services provided in Guernsey as well as existing components of care can be improved. However, Guernsey will not have a system that works around people without confronting the bigger structural issue. The 7 big themes and the 4 significant gaps in service that are listed in section 3 are discussed in more detail below.

The 7 Big Themes

1. The strategic planning role of the State is underdeveloped with serious consequences.

- Forward planning is lacking because the States has been unclear about its role as planner or provider. As a consequence there is a huge gap in information about almost every service and about the needs of the population. This must be reversed and the States must prioritise its strategic planning role.

- 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. There is a clear responsibility on the States to be the strategic planner. The electronic census will be rolled out gradually over the next year and that should provide a lot of data on the population, however that is only part of what is required in a good planning system.

- As a consequence the key skills of good commissioning have not been developed and this must be part of any planning framework. The control culture developed to account for spend has resulted in officers managing small detail instead of commissioning which is financially inefficient. (See definition of commissioning in the appendices).

- The States does not strategically manage the services that are outsourced. For example residential and nursing homes are not subject to service level agreements or strict regulation, which promotes improvement. Whilst the agreement is between the individual and the home there are ways of capping costs tied to standards and there are ways of ensuring that the sector responds more positively to taking older people with challenging behaviours. Another example is the GP service, which is critical to the system working in a coordinated way (see below).

- Another consequence is the inappropriate placing of services in departments, or in the wrong part of the system For example some domiciliary care services are managed by the Housing Department, and HSSD manages some accommodation. There are community support services such as stroke rehabilitation developed in the hospital setting when it is needed in the community.

- The States is also unclear about which services it wants to directly provide and which it wants to outsource. Conventional wisdom suggests that States' resources should be focused on the highest needs which is where its expertise lies and use voluntary organisations to provide low level support services such as befriending, shopping and cleaning services. This also makes best use of resources and money.

- The third sector and the private sector should also be able to tender for service provision but subject to clear standards and outcome achievements. Fostering the third sector should be part of the States strategic role

2. Information is lacking for planning purposes and for the public

- Three kinds of evidence, in particular, are important:

    - **Evidence** about the **local** need for a specific action

    - **Evidence** about whether the action can deliver the outcomes required.

    - **Evidence** about the ongoing effectiveness of existing or new services.

- Without such evidence, it is not possible to conduct effective strategic needs assessments or health impact assessments, which, together, identify the areas of greatest need and the most effective ways of meeting that need. Robust and accurate needs assessment requires reliable population data sources: demographic, epidemiological and clinical.

- There is little confidence in the information data systems that do exist and this was a most common theme in all the consultations. The population of Guernsey need better information that is accessible.

- In conducting this piece of work we found that information quality and records were variable across the services. Time devoted to different services is not logged accurately and historic trends are hard to come by.

- A lot of information that is available is not traceable to specific service users so it is not possible to tell if one individual appears on multiple caseloads or if social work and community nursing are seeing different people. This was a problem found in primary and secondary care. For example readmissions to hospital contained large numbers of people not being readmitted but going for planned appointments such as for dialysis.

- The implementation of the TRAK system should help to resolve some of these issues and it is being rolled out to areas that did not previously use it within HSSD. However, large parts of the system, in particular GP information in primary care, will still not be part of TRAK. The electronic census data project has made good progress and will start to be rolled out from mid 2014 onwards. SSD has significantly more information and much of it is published. There is good population trend data published annually.

- HSSD Community and Disability Services are also in the process of developing 'balanced scorecard' KPIs which will provide more outcomes based information about services. These are not yet fully implemented and it will be some time before data and trends are available.

- Indeed there are several important initiatives being developed which will provide important information but like TRAK there are concerns that these have been developed piecemeal and will not be comprehensive enough nor work in a coordinated way. However, they are important improvements.

3. The GP service must be reconnected to the rest of health and social care as it is so critical to the rest of the system working well for people.

- The GP service, whether public or private, is the entry point into health and social care systems in most Western countries. The role of the GP as the foundation block of any good health and care system has already been covered in section four on the framework, but it is worth reinforcing its importance to the whole system working well and why this is currently problematic.

- GPs have a wealth of knowledge about the population in their area and are essential to the way other parts of the system work to support people through sharing knowledge, signposting to other services and generally having a role to look after the well-being of their patients. GPs are the ones most islanders go to and trust in Guernsey, but their role in the whole system is limited and as a result other parts of the system suffer. They do not coordinate their services with other providers nor do they see their role as the general health and well-being of their community.

- They are the gatekeepers of primary care but share very little even with some parts of secondary care or with the States or voluntary support organisations. For example, specialist teams such as the Adult Disability team, which is an effective small multi disciplinary team, will not always know if a client has gone into hospital.

- Not all GPs have adequate information to signpost islanders to other relevant services and many are actually ill informed about what services and support is available. The weight of comments about this disconnect from the consultations suggests the need to review this in more detail and look for ways to change the position before the renegotiation of contracts in 2017.

- GPs are the access points but can't point patients in the right direction. They do not regularly attend case conferences and do not supply information to other providers unless paid for even where the patient has consented to the sharing of information. They do not contribute to the States TRAK information system. The ability to plan services without this information is, therefore, impossible and patients suffer.

- GPs are well organised and are mainly part of 3 partnership groups in Guernsey and 2 in Alderney. They have the capacity and capability of providing what the States needs as part of a whole system

4. **Islanders should have the choice to have care at home/in supported living accommodation or in a home. There should be a rebalancing of services in institutional and hospital care and community care. This will require a substantial development of social care services to support people at home.**

    - **All forms of community services are under developed.** This includes domiciliary care services, community mental health and dementia services, supported living accommodation, rehabilitation and re-ablement at home, respite and day care provisions and support to carers. There needs to be a shift from secondary health care to primary care and the development of services, which provide choices to have services at home. A hospital centric system will not be affordable in the future and it is not what people want. People require a choice of care and where that care is provided and on an equal financial footing.

    - The long-term care insurance whilst admirable in conception, only offers payments to people moving into private nursing and residential homes. It does not provide help to people who wish and are able to stay in their own homes or live in supported housing, even if they have the same needs. This has resulted in moves to residential and nursing care before it is needed.

- The health and social care system in Guernsey is founded on a view that sick people need to be in hospital and this has affected the structure of the whole service and limited the development of community care services. It has created a dependency culture where the States is seen as needing to provide everything. Bed occupancy has been manageable so people often stay in hospital a long time and some reported that they stayed there until their choice of care home had a vacancy. The move from hospital straight to a care home is very high. This incentive to move into residential and nursing provision too early is a costly model of care, does not promote self-care and is financially unsustainable.

- Some people also perceive care at home as costing them more. Support services are charged for and the cost of equipment and such things as incontinence pads can be high. They also see care at home as inflexible compared to residential care e.g. fixed visit times. Comment was made several times that it was "safer to move into a care home early as nurses will be on hand"

- Providing choices to people also requires good meaningful information about what is available. Since the planning role of the States is underdeveloped this is difficult and there was much adverse comment about this during the consultations. Advisory agencies likewise found it hard to find the right information for their callers. The CAB provided an analysis of the last 111 enquiries and 80 were about social care and health services.

- The choice to manage one's own care services through personal budgets and direct payments needs to be considered in Guernsey particularly for younger disabled people. In the UK personal budgets have been hugely successful with younger people, and it has revolutionized their lives, although they have been less popular with older people. (See definition of personal budgets in the appendices)

5. The system lacks overall co-ordination and this affects people's quality of life.

- Systems that have developed piecemeal suffer from difficult transitions between services and lack coordination of care overall and this at a time when needs have become more complex and people use several services at the same time.

- If care is to be centred on the person there is a need for high levels of co - ordination and someone who knows the person and the community in order to improve both the health of the individual and the community at large. Increasingly, General Practitioners are looked to in many countries to fulfil this role.

- Jersey, for example, has changed its contract with GPs to increase their responsibilities in community care. In the UK changes have focused on the critical role of the GP for people with complex conditions through what is called "the proactive care programme"[5]. This places responsibility on the GP to be the advocate for older people with complex care needs to ensure that services work in a coordinated way for them. The GP will also review services for that person post discharge from hospital.

- Coordination of services also requires early intervention through swift referral to support organisations, social care or secondary care and identification of people at risk using the many tools that have been developed but the role of the GP is again critical to achieving this.

- Services need to follow the person particularly after a period in hospital. All specialist nurses who currently work in the hospital and out-patient clinics should also work with people at home and support and train senior care workers in specialist care. This includes such specialisms as physiotherapy, pain management, stroke and other nurse specialists. It is interesting that mental health services are also part of secondary care and not primary care and this has created some barriers. Japan, for example, has made substantial changes to its overall integrated care approach[6] through providers who offer multi-disciplinary hospital acute services and community services which follow the person out of hospital.

- Excellent communication across services is essential through such things as shared data, and single assessments, which are available to all services. Testing the service by users is another important ingredient of coordinated care.

- The Guernsey system is fragmented and some essential services – such as GPs – are almost entirely independent of the States and do not work with other agencies

  "In the same way, the lack of legal or contractual relations between different parts of the system – such as primary care and secondary care, or service providers and policy-makers – means that organisations are free to follow their

[5] See NHS England (2014) "Enhanced service specification: Avoiding unplanned admissions: proactive case finding and patient review for vulnerable people". 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.england.nhs.uk%2Fwp-content%2Fuploads%2F2014%2F06%2Favoid-unpln-admss-serv-spec.pdf&ei=AF6NVde1GPSM7Ab6jqzAAw&usg=AFQjCNHtqYSaBFnRIya8QbD_dhUHDTFMJA&bvm=bv.96782255,d.ZGU

[6] Nuffield Trust (2013) "Caring for an ageing population: points to consider from reform in Japan". Available at: http://www.nuffieldtrust.org.uk/publications/caring-ageing-population-points-consider-reform-japan

own objectives, and there are few structural incentives for working together towards shared goals and quality standards."[7]

The roles of HSSD and SSD are complicated and ambiguous and often overlap. Whilst HSSD is responsible for policy and regulation it is not always the paymaster and SSD sets policy through payment decisions. SSD also contracts with MSG and GPG, and provides the individual subsidies for GP and nurse consultations and long-term care placements.

- Health and social care funding is also complex. All GP visits have to be paid for but secondary care is largely free. People, therefore, use secondary care when ever possible, which is expensive and takes up valuable consultants time when their conditions could be managed in the community by GPs.

- The following is an excerpt from an internal research report dated 2010, which illustrates the fragmented nature of the services very well.

> Mr D has diagnosed dementia and is being cared for at home by his spouse, who is ageing and unwell. Mr D receives a daily personal care service from Senior Carers, a regular visit from the Continence Nurse and a regular visit from a member of the Elderly Mental Health Team. The daily personal care he receives is delivered by a generic service with no individual tailoring to take into account Mr D's needs as a person with dementia. The communication between the Community Care senior carers and the Elderly Mental Health Service is very intermittent and tends to be precipitated by crises. Mr D and his family carer are frequently upset by the number of people caring for Mr D, which causes him anxiety and increased episodes of incontinence. His family carer reports that "the right hand doesn't know what the left hand is doing".

"This pen-picture describes a man whose needs are complex and which cannot be met by a single service group. Two service groups were providing his care: the Community Care Team and the Older Adult Mental Health Team in addition to the support of a specialist continence nurse".

The report goes on to say that "The same is true for people with learning disabilities who develop mental health problems. Professionals report that there is little inter-service working for people with complex needs that span service boundaries. This is problematic with an ageing population, as people with learning disabilities are four times more likely to develop dementias than the general population"

[7] Policy Council (2013) "2020 Vision: Progress Report and Next Steps" Available at: http://www.gov.gg/Hssd2020Vision

"Interviews with health professionals themselves confirmed an operating environment where services – mental health, disability, and community care - tended to operate in isolation from each other. Often there are multiple assessments of need as an individual moves from one service area to another."

- Whilst there have been some improvements in communication since 2010 there is still considerable silo working. The current situation is described as having better liaison between the Older Adult Mental Health Team and the Community Care Team but the former visits to draw up the care plans, which of course change frequently, and the latter actually deliver the care. It would be much more flexible and cost effective if the Older Adult Mental Health Team also had care staff within the team who could look after a number of people with complex needs.

6. **There is a big challenge to improve diagnosis, treatment and support for people with mental heath problems and to connect physical and mental health services.**

- The pen picture provided above illustrates the disconnect between mental health and other services and the section on pages 18 and 19 on dementia specifically outlines the issues with diagnosis, treatment and follow up for people with mental health problems.

- Dementia training is not compulsory either in community services, within the care homes, nor in secondary care. Whilst there are plans to introduce this in the future, this will only be for qualified nurses and not for all care staff.

- Roughly a third of people with physical conditions also have a mental health condition. (There is no statistic in Guernsey on this but it is likely that the figure will be similar to that in the UK).

7. **Relationships with and capacity of the third sector and the private sector**

- There is a need to develop the roles and responsibilities of both the third sector and the private sector but within a planned strategic framework.

- The private sector is a significant provider in Guernsey but the point has already been made that the GP service is not linked to the rest of the health and social care system.

- There are also significant issues with the relationship between the States and private sector care provider. There is a need for the States to develop closer partnership working with the private care home sector to enable the island to build capacity to cope with the increasing levels of dementia within the island's

private care homes. Currently very few care homes are willing to take people with complex care needs. There are still 77 beds continuing care beds in hospital, which need to be phased out so that older people have the dignity to live in a more private environment. In this way, the high costs associated with maintaining continuing care beds for the frail elderly can be re-invested in services which will deliver better outcomes for a wider range of people in community settings. There are no formal service levels agreements with care homes and whilst there is regulation, this is a blunt instrument.

- There is also a need to build capacity in the voluntary sector and ensure there are clear pathways for people to access their services. Guernsey benefits from having a significant number of voluntary support organisations and in recent years some have developed and matured to the point where they are ready to become significant service providers by tendering to the States. Voluntary organisations can provide many of the lower level services so that the States can concentrate its resources on more complex care within the community. There are some support activities where Guernsey could benefit from attracting a large established provider to the Island. Carers UK is one such organisation. Another is Elderly Care Accommodation who provides advice and guidance to older people on all forms of housing.

- Given the need to make economies, the States would also benefit from looking more to the private sector to build supported housing for older people, which is popular. An internal research report of 2010 states that "Public Partnerships to deliver housing units will be necessary as public sector money to develop social housing becomes more and more limited, but careful consideration relating to strategic land planning and the implementation of land planning legislation and policies will also be required to identify and maximise development potential across the whole island in the most effective manner."

The following 4 gaps in the service were also identified and were the subject of much comment during the consultation discussions.

1. Support for carers is very limited

- Carers must be recognised and valued for the important work they do in supporting vulnerable people and enabling them to remain living in the community

- Carers need to be equipped with the skills, knowledge and information required to perform their caring role

- Carers need to retain their ability to participate in society and may need support or additional help to enable this

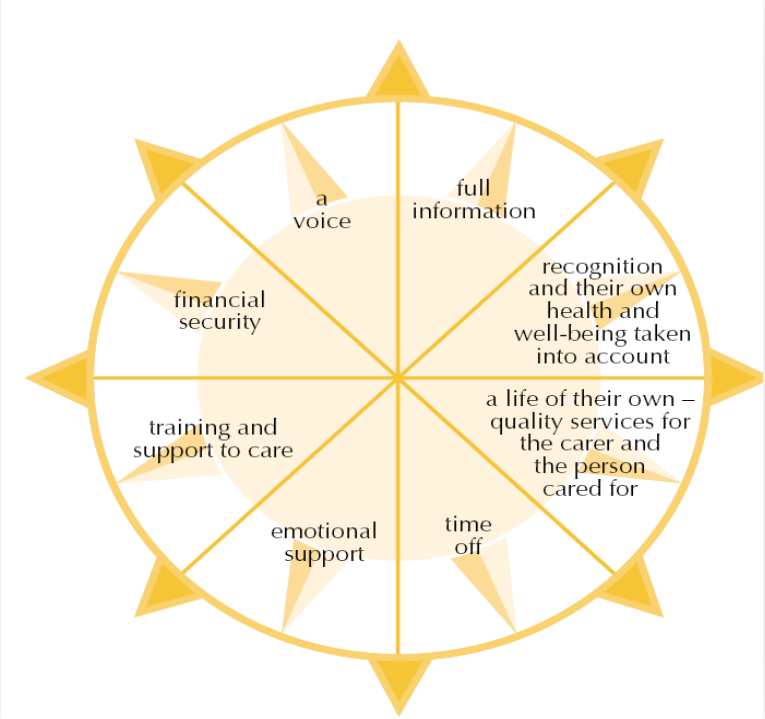
- Caring often reduces a carer's ability to work and earn a living so carers need help and support to remain working or to re-enter employment.

The Disability Needs Survey[8] estimated that 1 in 10 of all households (8%) have at least one person who provides informal and unpaid care for a family member, relative or friend. This adds up to around 2,080 households or an estimated minimum of 3% of the population (some households might have more than one carer). 1 in 5 of the estimated 14,000 people with long-term conditions (21%) live in a household with someone who provides unpaid care and support. Carer's needs are often forgotten or assumed to be the same as the person they care for.

The **carers compass**[9] is a good pictorial illustration of the needs identified, although this report does not cover employment issues or the environmental issues.

[8] BMG (2013) "Disability Needs Survey: Review of prevalence across Guernsey and Alderney". Available at: www.gov.gg/disabilitystrategy

[9] 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



There are several strands of need identified:

- **Firstly**, **more general support**. There is a Carers Association in Guernsey but it is very small and has limited capacity. Other voluntary organisations such as Mind at their community centre and the Guernsey Blind Association amongst other also provide some support. However, they lack real capacity. Guernsey would benefit from an organisation like Carers UK, which could have an affiliated branch on the Island and provide it with the backup support of a larger organisation.

- **Secondly**, a carer's assessment, which would identify the support carers needs to continue caring. This is being piloted at the moment. At the time of writing the Disability and Inclusion Strategy this was not happening and the following quote illustrates the feeling from islanders.

  "Carers are at risk of becoming isolated from their own natural support group – family, friends, colleagues and so on – the more time they spend caring. … Caring for another person is one of the most valuable – and least valued – roles in society. Assessment for community care services and for respite care services

do take into account the needs of carers but these are not the primary focus and there is no support put in place purely for carers."[10]

"Mind" was particularly concerned about out of hours support to carers of people with mental health problems People for example who are suicidal can take a turn for the worst anytime so the carer has to be constantly vigilant. The strain on the carer is often too much.

- **The third need** is for support in the form of training particularly about dementia. Carers need to know more about the disease and how it will progress so that they have coping strategies.

- **The fourth need** is information for carers. Many quotes in section 7 illustrate this. The Disability and Inclusion Strategy says "The development of information services, both in general and at specific transition points will 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."[11]

  Older carers in particular say they did not know they were carers or that there was help available for them including some financial help. Very few claimed the carer's allowance. Many of the moves by couples into residential and nursing care seem to happen when the carer also becomes ill. Families say they need information about the suitability of different care homes.

- **The fifth need** identified for carers is respite care – see below.

2. More respite care is needed.

The respite care service was singled out as a service that is inadequate to both assist carers and assist the people being cared for. It is also one of the "quick win" recommendations in section seven of this report.

The kinds of break needed are:

- Short residential stays for the person receiving care

- Sitting services where somebody (could be a volunteer) comes and sits with the person receiving the care while the carer goes out or has some time off

The current situation seems to be that:

[10] Para 109, Policy Council (2013) "Disability and Inclusion Strategy", Billet d'État XXII, 27th November 2013.
[11] Para 114, *Ibid.*

- Guernsey does offer a limited sitting service run by HSSD, which can help when a carer has an appointment but this needs to be booked some time in advance.

- There is 1 respite extra care flat for older people and 2 for all age groups.

- There are 2 respite beds at the Duchess of Kent which are for older adults with mental health conditions or dementia and a further 2 respite beds on the Lighthouse Wards which are for complex physical needs.

- There is 1 respite bed (which HSSD pays a year round nursing bed rate for to keep it open) at Summerland Nursing Home – this is most suitable for adults with nursing needs and 1 respite bed in Cheshire Homes which is for nursing care status for adults with physical disabilities and complex needs.

- Finally there are 2 reserved respite beds at Beauville, which is a community home for people with Learning Disabilities.

- Other residential and nursing care homes do take people for respite but this tends to be when they have capacity and there was none available at the time of writing this report.

The Needs Assessment Panel (NAP) issues certificates for respite care in order for Social Security to authorise long-term care benefit payment. In the first 6 months of the year NAP issued the following respite certificates: Hospital respite, 5 (Lighthouse wards); nursing respite 25 (including Cheshire Home and Summerland); residential respite, 58; residential EMI respite, 10; extra care respite, 6.

They also noted a shortfall of 26 respite placements for first 6 months of 2014. This is in addition to the many people who do not ask for respite because they know it will be unavailable. All professionals who took part in this work were concerned about the lack of respite help available and what was available was usually for an emergency only.

3. There is a need to develop adult mental health and dementia services

Guernsey has made huge improvements in supporting adults with learning difficulties and mental health problems, although much more needs to be done. In 2012 Guernsey published a comprehensive report on Mental Health and Wellbeing in Guernsey[12] and Alderney. The new strategy includes building a £24m mental health centre in Guernsey on the grounds of the Princess Elizabeth Hospital, which will replace the Castel Hospital, which is expected to open in 2015.

[12] HSSD (2014) "Mental Health and Wellbeing in Guernsey and Alderney – Research Report", Available at: http://www.gov.gg/mentalhealthandwellbeing

The real gap is in dementia. Both understanding and care is poor. Dementia is a huge challenge around the world but Guernsey does lag behind some of the countries it would normally compare itself to.

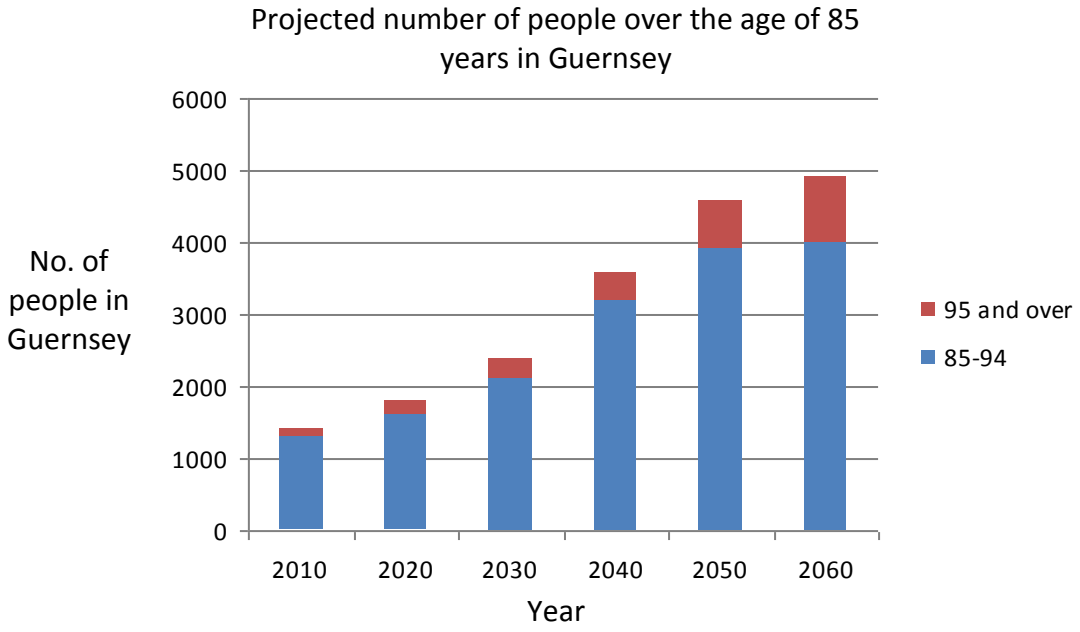
The UK developed its first major National Dementia Strategy[13] 5 years ago and it is only now that the government can say that most local authorities have dementia plans in place. This strategy is informing Guernsey's approach.

The strategic objectives of the National Dementia Strategyare listed below to highlight the kinds of provision for people with dementia that the Island needs to move towards to meet the challenges that the ageing population is presenting:

- Improving public funding and professional awareness and understanding of dementia
- Good quality early diagnosis and intervention for all
- Good quality information for those with diagnosed dementia and their carers
- Enabling easy access to care, support and advice following diagnosis
- Development of support and learning networks so that people with dementia, and particularly their carers, can talk to and learn from other people who have experienced the same issues
- Improved community personal care and support services so that people with dementia can receive a range of services designed to meet their specialist needs within their own home
- Implementing a Carer's Strategy
- Improved quality of care for people with dementia in general hospitals
- Improved intermediate care for people with dementia
- Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers
- Living well with dementia in care homes

[13] Banerjee, S and Own, J. (2009) "Living Well With Dementia: A National Dementia Strategy", UK Department of Health

The graph below demonstrates the projected growth in the population of people who are very old – those aged between 85 and 94, and those aged 95 and over. One in five of older people over the age of 85 will have some form of dementia.



Some of the issues identified in this diagnostic stage of the work for SLAWS include: -

- Some concern was expressed by the Older Adult Mental Health team that some GP's had limited knowledge around identifying and diagnosing dementia.
- Lack of resources to follow up patients after attendance at the memory clinic, which has been in existence since 2003.
- Families who reported being relieved when they did receive a diagnosis but had to wait for a long time for the information.
- Many people going without a diagnosis (in the UK it is still only 50% of people with dementia who have been formally diagnosed[14].)
- Carers without information or support to understand dementia. No carer sessions were available.
- Very limited good residential and nursing dementia care available in the privately run homes, hence the very large number of 77 continuing care beds.

[14] NHS England (2014) "NHS England Chief Executive committed to improving dementia diagnosis", online news article, 10th September 2014. Available at: http://www.england.nhs.uk/2014/09/10/dementia-guide/

- Aninternal research report emphasised the lack of availability of beds in care homes for older people with dementia in care homes.

  "Accepting that most people with more moderate to severe dementia will require institutional care, there is a pressing need to ensure that private care home partners are able to respond to the need for increased provision of specialist care within residential and nursing home settings. The development of Maison de Quetteville by Methodist Homes for the Aged (MHA) is a heartening development in this regard as MHA has an excellent reputation in the UK for providing specialist dementia care.

  However, there remains a need for the States to develop closer partnership working with the private care home sector to enable the island to build capacity to cope with the increasing levels of dementia within the island's private care homes."

- The Older Adult Mental Health Team expressed concern about the limited number of private homes able to support people with dementia. Concern was also expressed about the private homes being able to select service users that they wished to care for which may result in service users being inappropriately placed. Training in the care homes is limited and not mandatory which needs to be addressed urgently and ensure that the training provided recognises the uniqueness of each individual with dementia and the need for care to have a person-centred approach.

  The German experience is interesting to note. They have put resources into celebrating what people with dementia can do – to celebrate a good life with dementia. Their research has shown that people with dementia who participated for 2 hours a day in their cognitive stimulation programmes do not see their dementia advancing. The programmes include things such as music, dance and other activities people used to enjoy. Germany is trying to change attitudes towards dementia and ensuring that people with dementia participate in what makes the rest of us happy - be that seeing the leaves change colour in Autumn or singing. They are moving the focus from the day-to-day misery of dementia and in favour of what makes people happy.

4. There are gaps in the provision of housing with care.

Supported housing for adults with learning difficulties and mental health difficulties

- In particular the supported housing options for younger adults with learning difficulties, mental health difficulties and physical disabilities are very poor.

- An unpublished report on residential provision for adults with learning disabilities and mental health difficulties has been produced by HSSD recently and, whilst it has not been discussed or approved at political level yet, it provides an analysis of the current position and some assessment of future need. It states that:

  "The principle advocated in this paper is that where possible buildings should be key enablers to facilitate high quality service delivery and the aspirations of individual service users. Suitable accommodation is a keen determinate in an individual's wellbeing and mental and emotional health".

- It goes on to say that the buildings used by Guernsey are often a blockage to good service delivery as most buildings are old adapted houses and maintenance has been poor. The report states that HSSD owns 13 buildings providing 63 residential places to adults with Learning Disabilities and Mental Health difficulties, which are mostly unsatisfactory. It also rents some others on a short-term basis. This is 46 beds in 7 buildings for adults with learning difficulties almost all of which are deemed unsuitable. There are 20 beds in 4 building for people with mental health problems, which are less problematic.

The key findings are that:

- Most buildings are unsuitable for the current use, have not been well maintained and have been a piecemeal response to specific challenges. There has not been an over-arching strategy or plan.

- There is a lack of choice for service users as there has only been 24/7 residential care, living at home with parents/carers or a placement off island. Expectations are now changing and Guernsey needs to respond positively. Service users want more independence and their own home.

- There is an urgent need for purpose built independent living accommodation and the opportunity of moving 15 people into extra care apartments will allow the re-configuration of the service and buildings if money can be found.

- The service is not person centred.

It defines the current need for accommodation, which is: -

Adult learning disability accommodation

- A group home of 4 single flats and communal accommodation to replace current out-dated accommodation and bring people back from off island.
- A group home specific to autism of 5 single units with communal facilities.
- 4 flats in close proximity as replacement accommodation
- 6 flats in mainstream accommodation to meet current demand.

Mental health provision

- 6 single flats in main-steam housing to meet current need.
- 4 flats located in the same area to replace out-dated facilities.
- A block of 6 flats with communal facilities to replace existing facilities.
- A property with 2 separate bedrooms to replace existing accommodation.

The report is less clear about future needs although it does extrapolate current experience into the future. Proper data analysis as proposed earlier in this report would improve service planning.

Housing with care or support for older people

- An internal research report from 2010 argues that the current structure of both public and private housing provision in Guernsey encourages older people to migrate from their homes in the community directly into residential care.

  "Because of the lack of housing which provides low level support for individuals, like sheltered housing, residential care in the island has in many instances replaced sheltered housing provision and accommodates many residents who have relatively few care needs. The gap in sheltered housing at the lower end of the dependency spectrum has, in effect, pushed individuals needing lower dependency housing and support higher up the dependency provision scale. This is costly in terms of money and in terms of decreasing wellbeing and independence."……. "Older people with disabilities or who are frail are being referred to residential care because of the lack of accessible housing forms, which provide support or care services. In order to reduce reliance on institutional care, we must provide more specialised housing".

  "This means that people whose needs could be met by sheltered housing are in residential care; people whose needs could be met in residential care are in

nursing care; and people whose needs could be met in nursing care are in continuing care hospital wards at the King Edward VII hospital. In the UK, it is very rare to find individuals being cared for in continuing care hospital wards – these individuals are more appropriately placed in nursing homes and hospital is reserved for illness and acute medical needs."

- It is difficult to be precise about the needs because the States has not developed its planning role. However, Guernsey has 199 flats in extra care (some just coming into management) plus 45 in development and 20 public housing sheltered flats in management and 14 in development. Again interestingly there are different figures in different reports or data sets. In the private sector we think there are around 268 but this is hard to verify. The overall total seems to be 546. But 15 (possibly more) are for use for adults with learning difficulties and not older people so the number to use is 531.

  In addition there are 461 residential care beds and 236 nursing beds. Again need is harder to assess but throughout the interviews conducted it became clear that more nursing provision in the private sector was needed and less residential because of its limitations.

- We can compare the numbers in these forms of care and supported housing in the UK because all have been available longer than in Guernsey. The figure is 5% of the population over the age of 65 live in sheltered or extra care housing and another 5% of older people in the UK live in residential and nursing care. In Guernsey the population of older people over the age of 65 is 11,175 so using 5% Guernsey could expect to need approximately 559 flats of extra care and sheltered housing and another 559 places in residential and nursing homes.

  In reality 6.2% of older people now live in residential and nursing homes and approximately 4.6% will be living in extra care and sheltered housing when the homes in development are completed. (At the moment it is very low).

- This does seem to tally with the 1996 Board of Health strategy figures that set out the following projection for sheltered housing need based on a comparison of Guernsey and UK indices. Projections were based on comparing the number of sheltered housing units per 1,000 older people in the UK and applying this formula to Guernsey.

Need in 2001	Need in 2006	Need in 2011	Need in 2016
432	452	473	548

- "However, demand for extra care housing in the UK is very high and the private sector is keen to develop more of it for sale and part sale and release much needed family accommodation. There is considerable wealth amongst some older people on the island and the flats for sale at Rosaire Avenue were in high demand with a long waiting list of unlucky would be purchasers. Guernsey could move towards the private sector in partnership satisfying this demand, which would have the combined effect of releasing residential and nursing provision without giving up the inheritance that seems so important in Guernsey." (Internal research report of 2010)

- The largest single provider of 'sheltered' housing in the Island is Guernsey Sheltered Housing Group Limited, who has developed a stock of 146 units since 1986. Including turnover of existing units, this represents average availability of 9.6 units per annum over the 24-year period to 2009 (5.4 units average availability over the last 5 years). There is 100% occupancy of their units and a waiting list that extends to 357 persons, indicative of the unmet demand for this kind of retirement housing in Guernsey. (Internal research report of 2010).

- There seems to be good capacity in the residential and nursing sectors but not necessarily of the right kind of provision. Guernsey needs to strategically manage the provision better by encouraging more accommodation for older people with dementia and more challenging behaviours to reduce the number of continuing care beds it provides in hospitals.

Section six: Components of Care in more detail

What is good practice in each component of care is described, and then compared against the position in Guernsey. There is then a section containing comments raised through the consultation, which backs up the conclusions about Guernsey's position. Some are non-attributable quotes; others are paraphrased views of large numbers of people. This section provides much of the detail about how the health and social care system works for people in Guernsey. It is from this that the key themes have been identified and given the similarity of issues raised by people when talking about any of the component of care it adds a great deal of weight to the key conclusions. This section is, therefore, not only the bulk of the evidence about issues in the Guernsey system but gives a way of measuring changes/improvements as they are made.

1. Healthy, active ageing and supporting independence

Essential components

This can be applied on a number of levels.

- Population health can be protected by screening and immunization, annual personal "MOT's" and healthy living campaigns.
- People should have access to support as early as possible.
- Individual health crises should be avoided by taking steps to detect or diagnose health risks as early as possible, perhaps using targeted approaches to direct resources, and evidence-based risk assessment to ensure the most appropriate interventions are made in primary care.

This is, therefore, not just about "encouraging personal responsibility", which is one of the States' objectives, but also about encouraging different service providers to work well together – for example, sharing experiences and not passing on costs unnecessarily – to get the best outcomes for the people who use their services.

Guernsey position

- Guernsey has a life course approach to ageing, and is about to start the 6th healthy lifestyle survey[15] (there was previously a cut off at the age of 65 but the survey is now going out to all ages).

[15]HSSD and Centre for Public Health (2013) "Guernsey and Alderney Healthy Lifestyle Survey", 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.cph.org.uk%2Fwp-content%2Fuploads%2F2015%2F01%2FGuernsey-Healthy-Lifestyle-Report-2014-12th-December-

From this we know that life expectancy from birth is on a par with Jersey and slightly higher than the UK. We know about preventable deaths, such as winter mortality, and about levels of anxiety and depression amongst the population. We know that the take up of immunisation against flu is only 50%.

- There is, therefore, some good data and an ability to monitor changes over time. However, some of the resulting strategies that try to address healthy living do not include on-going collection of data nor have clear measurements of success.

  Some of the strategies also miss an older person's dimension and it would be good practice to have an older person strand of all public health policy which makes it clear that older people should have access to the same things as younger people for example good nutrition, exercise and regular lifestyle check-ups.

- GPs do not routinely provide information to public health analysis despite having some of the best information because they are not contracted at a population level and Guernsey may be the only jurisdiction that does not require its GPs to take an active role in community health management.

Key points from the consultation process

- Some good approaches are in place to deal with such things as obesity and smoking but none have had an older persons champion to comment on them.
- GPs hold much of the information on public health but do not share it.
- The GP service should be a health not a sickness service and needs to operate at a population level like Jersey. "Actions such as advocating an aspirin a day would make a huge difference to strokes".
- Guernsey must act early to prevent crisis or deterioration. GPs are critical to early identification and prevention. We also need protocols around how they diagnosis such as dementia e.g. contact with the Older Adult Mental Health Team.
- The Guernsey Healthy Lifestyle Survey[16] reports that there is significant older people's poverty on the island and significant issues of nutrition, bone health and incontinence, all of which can be managed and prevented.

Final.pdf&ei=x26NVfSPBZCO7Aadp6HQBA&usg=AFQjCNGdznnz18VBNuS8RW99SVRY_2GY8g&bvm=bv.96782255,d.ZGU

[16] HSSD and Centre for Public Health (2013) "Guernsey and Alderney Healthy Lifestyle Survey", 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.cph.org.uk%2Fwp-content%2Fuploads%2F2015%2F01%2FGuernsey-Healthy-Lifestyle-Report-2014-12th-December-

2. Living well with simple or stable long term conditions

The focus on self-management of long-term conditions is critical in the face of large numbers of people living longer including younger adults with previously life limiting conditions and the cost of care.

The ageing population means that larger numbers of people are living with common geriatric conditions that need to be well-managed – poor vision, osteoporosis, urinary incontinence and arthritis. The role of the GP is crucial.

Effective management of long-term condition such as osteoarthritis, cardiac failure, chronic airways disease and non-insulin dependant diabetes, disabilities and stable mental health conditions means that individuals can remain active and independent in their own homes.

Important aspects of self-management at home include:

- Early identification and intervention at primary care level.
- A well-developed community care service backed by specialist falls clinics; district nurses, specialist nurse advisors and GPs who can help people to remain at home often for life.
- Nurse specialists and mental health services operating within community care to support such conditions in a coordinated way. This is often most effective where staff operate in multi-disciplinary teams.
- Generic care staff trained in mental health as well as physical health issues. Dementia training and awareness should be a requirement for all care staff.
- Good support to carers. The crucial role of carers in maintaining independence for older people and younger people with disabilities is well recognised and is in fact one of the key priority strategies of the World Health Organisation.
- Availability of personal budgets and direct payments for younger disabled people which offer them greater choice and independence. Personal budgets have revolutionised lives of younger disabled people in the UK. (See appendix 1 for the definition).

The Guernsey position

The Disability Needs Survey[17] estimated that nearly 14,000 people have long-term conditions in Guernsey and Alderney. Most of those islanders are not significantly

[17] BMG (2013) "Disability Needs Survey: Review of prevalence across Guernsey and Alderney". Available at: www.gov.gg/disabilitystrategy

disadvantaged on a day-to-day basis, but this figure also includes an estimate of 4,000 that experience difficulties in their daily lives.

The relevant parts of the Disability and Inclusion strategy are in **appendix three** including the areas delegated to SLAWS to address.

The three issues for Guernsey are:

- **Firstly,** there are very limited resources available to people to help them manage their own conditions at home. Without early intervention people go into hospital.

  The community care and support service to manage these conditions at home is inadequate and underdeveloped. HSSD report more people are supported at home but this is mainly end of life care and other care packages have to be fitted around this priority. The reported increase is from a caseload of 288 in 2009 to 714 for the year to March 2014. Figures for domiciliary- unqualified staff -has risen from a caseload of 267 in 2009 to 358 as at March 2014. Home help and handyman services have increased a caseload of 214 in 2009 to 368 in March 2014. All these figures are low for a population of over 11,000 people over the age of 65. There are some concerns about the overlap in the reported caseloads because if the same person is seeing several professionals they may be reported in several caseloads making the total number of people seen by community services hard to estimate or analyse, again, highlighting the need for patient-specific data.

  The Long-term Care Insurance Scheme provides incentives for people to move early into residential and nursing care because the bulk of the funding is provided. The fund will not, however, pay for equivalent care at home even if that would be cheaper. Whilst care at home is no longer means tested there are costs the user must cover such as equipment and pads, support services such as shopping and cleaning and there can be a significant wait for the service.

  It would be a good investment to reskill people rather than move them to more expensive options especially when only one of a couple needs the care.

  Whilst some specialist nurse work in the community as well as the hospital, this is limited to the palliative care nurse (2 posts), the tissue viability nurse, the continence nurse and the MS nurse attached to the MS Society. Others only work in the hospital and out-patient clinics.

  The only other members of the community care service who can provide personal care are the senior carers but because they are relatively untrained they focus on

simpler conditions. Other staff in this service provide low-level support such as shopping and cleaning. All the nurse specialists agreed that they should be able to follow the person from hospital to home and also work with people at home as well as provide more training to senior carers in specialist skills.

- **Secondly**, GPs are not part of the coordinated support cycle. An example of good practice would be for people with suspected heart or confirmed heart failure being assessed jointly by a nurse specialist and GP who agree a shared care plan for treatment, management and self-care for the patient. GPs are also the gatekeepers of much of the information needed for planning services to this group of people, e.g. patients with insulin dependent diabetes, end of life register.

- **Thirdly**, partnerships with voluntary organisations are under-developed. Whilst there are voluntary organisations that offer specialist support to people with long-term conditions such as sight impairment, strokes multiple sclerosis, they do not routinely get referrals nor help and their services could be better integrated into the system. Some are keen to become service providers through building capacity and tendering for services. There are also other models of collaboration being tested such as the nurse specialist being located within the MS Society. A strategic look at this could be very beneficial.

Key points from the consultation process

Overwhelmingly, the comments centred on the need to develop more community care services to support people at home. This has been a debate in Guernsey for some years and there appears to be broad agreement but there has been limited action. It was reported that the closure of the King Edward hospital was going to provide resources to develop community services but the money was not made available. "This was seen as a lost opportunity."

These were typical comments made by large numbers of people.

- "A service at home is hard to access".
- There are high referral rates to secondary care because it's free but many conditions such as diabetes can be managed well in primary care
- HSSD should be prioritising more acute community services and partnering with the voluntary sector to provide lower level support.
- Specialist nurses who do go into the community were highly valued and very well thought of. "Never a time when I did not have someone to call when I needed it … in 23 years."

- "The nurse specialist service provides excellent care."
- Nurses should be able to do more prescribing which has been proven as cost effective.
- Whilst institutional care is very necessary, Guernsey needs to shift the balance to offer more community services.

3. Living well with complex co-morbidities, physical and mental disabilities, and dementia and frailty for older people.

Essential components

We can also support people with more complex conditions to remain at home but it is more challenging and requires more coordination of services. The existing health system, which is dominated by a single disease approach, struggles to deliver care packages for people with multiple conditions particularly when people need mental health as well as physical support and care.

People with multiple conditions regularly have periods in acute care and coordination in the system is required to manage the transition from hospital to home and vice versa. Vertical communication between primary and secondary care systems is essential.

Whilst many of the same skills are needed to support people with complex conditions as are needed to support people with more stable conditions, there is, in addition, the need for rapid response, day centres, and respite care.

Supporting carers through advice, guidance and respite when needed is even more critical as the strains are huge.

The Guernsey position

- There is no long-term care strategy for people with complex needs and people with complex conditions end up in hospital and then move directly into a residential or nursing home. HSSD has started to develop a long-term conditions framework, which will tell service users what they can expect, and HSSD can be measured against this. Currently services are not evaluated against the patient's journey.
- Services to people over the age of 65 with mental health issues are shared between the three continuing care wards, the community mental health team and the complex physically frail team.
- There are plans to move to a needs led service rather than an age related service. This might offer more flexibility.

- There are no specialist dementia care teams operating in the community. Staff believe that more people could be supported at home if they existed. Care plans are currently devised by the adult mental health team but delivered by the generic senior carers team who are largely untrained in mental health issues. Whilst there are plans for the future to introduce compulsory dementia training this will only be for registered nurses and not care staff.

- Working with GPs is challenging. They do not always recognise nor correctly diagnose dementia according to HSSD specialists, and often the window of opportunity to use effective drug treatment is missed because of a lack of dialogue between HSSD specialists and GPs. Interestingly, the Alzheimer's Society and the Alzheimer's Association reported the same issues over lack of contact between them and GPs when they could be supportive to the patient and their carer.

- For younger people with complex conditions including mental health issues, things have improved in the last 3-4 years. However, the community mental health services report that being a small service, they can usually only support people in crisis.

- Carer's support is limited and often fails people when they most need it. More respite services would be a quick win to allow carers to continue caring rather become ill themselves.

Key points from the consultation process

- Three themes predominated. Two focused on big gaps in the service, which are, firstly, dementia and mental health community services for older people and, secondly, the gap in services and accommodation for younger adults with support needs. The third theme was carer's support**.**

- For older people with complex needs the big issue was the lack of community support and in particular the disconnect between mental health and physical health services

- The GP service was of concern because of the lack of training and understanding of dementia and their readiness to suggest residential and nursing home care before exploring community care services.

- For younger people the concern focused on the lack of specialist-supported accommodation and situations where younger disabled adults were moved into care homes where there is perhaps a 40-year age gap between them and the next youngest person. Overall there was reported to be a shortfall of accommodation

with support, which offers more independence to younger adults than residential care homes.

- There were views about the limited day care facilities available although the MIND centre is broadening the range of support it can offer to younger people with many different conditions. One example cited was the use of the Cheshire Homes day centre but this is geared towards people with serious physical disabilities so it lacks some of the facilities people with learning disabilities require.

- There were many issues reported about the issues faced by carers. The lack of support in general to continue caring for people with more complex conditions and dementia and mental health in particular. “I did not know I was a carer…. I looked after my husband full time because it was my wish”…. “We had to move into nursing care because I became ill too”. There are also issue about financial support. Many care home residents cared for a partner and very few said that they knew about the Carer’s Allowance.

- A recurring theme was the inadequate respite facilities for adults younger and older and their carers. Respite services are very limited and there is no allowance for a carer to have respite through a relative taking time off work and being paid. This is cheaper than a week in residential care.

4. Rapid support close to home in time of crisis and good reablement after acute illness and injury

Essential components

This is part of the wider strategy to help people stay at home, prevent unnecessary hospital admissions and prevent deterioration. Carers provide much day-to-day care to their loved ones but there are often crisis, especially in mental health.

As well as respite care at home or close to home to give carers a break, there needs to be good crisis response to prevent a crisis and unnecessary hospitalisation. It should be a multi-disciplinary team able to respond within hours and out of office hours. Many providers use the same team to offer intense services after discharge from hospital and this allows for a greater range of disciplines in the multi-disciplinary team.

The Guernsey position

- The sitting service is small but can cover for events with advanced booking, however, emergency respite is more difficult to access.

- There are not enough places for respite particularly for younger adults. This is one of the major themes picked up earlier.

- There is a small community rapid response team and there are plans to include reablement and rehabilitation at home so that HSSD can provide good post-hospital support as well as prevent unnecessary hospital admissions. Funding is still to be found. HSSD understand the need for this service.

Key points from the consultation process

- The responses from users of care services majored on the lack of respite care provisions, which is so important particularly when there is a crisis. Respite care or the lack of it is a very emotive subject in Guernsey.

- There were also some anecdotes from carers and those cared for that rapid response nurses were ill equipped for some long-term care situations For example, nurses unable to use oxygen pumps because of lack of training.

5. Good hospital care and other forms of secondary care when needed

Essential components

- People universally want to be treated with dignity and receive care that is compassionate and person-centred. In addition, they need rapid access either through Accident and Emergency or via a referral from their GP.

- People also expect to be treated by someone who is specialist in the area of medicine they need.

- For older people, things can be more complicated as they often have multiple issues both mental and physical and may be frail. It is good practice, therefore, to have a comprehensive geriatric assessment by a consultant gerontologist as soon as possible to stabilise condition, assess levels of frailty and plan as early a discharge as possible. There is evidence that elderly care units or wards deliver high quality care.

- It goes without saying that people fear hospital diseases. Deep veined thrombosis, good hydration and bowel movements, pressure sores, falls, mobilisation, uncontrolled pain are all risks in hospital that need regular monitoring and reporting to the public.

- For people with dementia, familiarity even in hospital is all important so the involvement of carers can be very helpful as well as staff who have been well trained to work with people with dementia.

- In order for there to be smooth transitions between home and hospital and back again, there should be rapid and automatic notification to other parts of the health and social care system via shared information and data systems.

The Guernsey position

- There is easy access to acute hospital care with short waits in Accident and Emergency. There appears to be only limited pressure on beds and sometimes people stay in hospital for long periods.

- Care is rated good but sometimes patronising especially towards carers who are not always well enough involved in care plans and discharge arrangements.

- MSG is the route for secondary care consultations and is generally well thought of. Waiting times are low and there is a good range of specialists. The problem for the future is that medicine is becoming even more specialized and will Guernsey be able to afford all the specialisms it wants on the island?

Key points from the consultation process

- Comments about hospital care were generally favourable. However, there was a view expressed by a few people who believed there was ageism in the service with decisions not to treat older patients. It is difficult to substantiate these views.

6. Good discharge planning and post discharge support

Essential components

- Hospital stays are not good for anyone and the longer a person stays in hospital the less able they are to gain independence. Longer stays lead to muscle loss, loss of confidence and dependency and it is costly for the States. Poor discharge planning leads to unnecessary readmissions.

- Discharge planning should happen almost as soon as a person is admitted and be part of routine practice involving the person and any carers.

- Home from hospital services, which provide additional support in the immediate post-discharge period, prevents re-admissions and there are good examples of the voluntary sector playing an important role in this.

- There needs to be a smooth transition to on-going care services and preferably to a trained re-ablement staff team which can support the carer and the person being cared for.

- Post-discharge support almost always requires some form of specialist nursing or physiotherapy input and wherever possible this should be in the home not in an out patients clinic. Good practice suggests that services should follow the person wherever possible.

A report by the Nuffield Trust in the UK gives a good example of how Japan provides integrated person centred approaches to discharge from hospital[18]. They bring together the discharge nurse and care manager before the person leaves hospital and a case conference is held including clinicians and health professional and relatives involved with the person's care. There is also a strong network of volunteers who offer sitting services to people in the community. They also have recovery wards, which are similar in the UK to rehabilitation wards.

The Guernsey position

- Guernsey does have a discharge planning system but as there is limited pressure on beds there is no urgency to get people home. It is, therefore, started too late.

- Carers' assessments are being trialed but to date the views of carers and their own needs is not high on the agenda. Discharge is agreed between social workers and hospital staff but it is seen as more of a medical discharge when it should also cover the social circumstances of the patient. There is no weekend discharge.

- There is good rehabilitation and re-ablement and physiotherapy in the hospital and then in out-patients but not in the home. Staff would like to see less of a barrier between secondary care and primary care. The physiotherapy contracts are due for renegotiation in 2017 so this is an ideal time to reconfigure this particular service.

- There is a big issue about the numbers of older people with more challenging behaviour who are cared for in the three continuing care wards in the Hospital because there are no suitable places for them in residential and nursing homes.

[18] Nuffield Trust (2013) "Caring for an ageing population", Available at: http://www.nuffieldtrust.org.uk/publications/caring-ageing-population-points-consider-reform-japan

Key points from the consultation process

- Rehabilitation prevents disability and loss of confidence. Lack of this service probably accounts for the numbers who go directly into long-term care.
- The service in Guernsey does not follow the person after acute hospitalisation e.g. the strokes coordinator is hospital-based but desperately needed in the community when a patient returns home after a stroke.
- "Specialist nurses should spend more time training generic staff."
- "The opportunity to develop Intermediate Care[19] services in Guernsey using sheltered or extra care housing units should thus be explored. Intermediate care services are common in the UK and were developed to ensure active recovery and rehabilitation and to prevent unnecessary loss of independence in older people and other care groups".
- "Guernsey should use the rehab ward better".
- HSSD has set up its own barriers between secondary and primary care. Services could follow a patient from hospital but many services are only available in the hospital.
- The continuing care wards were not seen as a suitable place for older people to live for long period of time. There were quite strong feelings about the need to ensure care homes did not pick and choose who they wanted and thus avoid taking the more difficult older people.

7. High quality nursing and residential care homes and other forms of supported accommodation for those who need it

Essential components/older people accommodation

- A good care home or supported living accommodation should maximise independence and quality of life not just care and offer care that is dignified and person centred and consistently high standard.
- Providers should be able to minimise unplanned hospital admissions, and when this is unavoidable ensure that there is good discharge and post hospital rehabilitation.
- For older people, good end of life planning is important which allows the person to die in familiar surroundings if possible.
- Excellent dementia training should be standard and mandatory.

[19] Intermediate Care services enable people to improve their independence and aim to provide a range of enabling, rehabilitative and treatment services in community and residential settings.

- The States should actively commission the care with clear standards and specifications enshrined in contracts.
- Regulation should be outcomes based and involve users and families.

The Guernsey position/older people's accommodation

- The biggest issue is that residential and nursing accommodation is not managed by the States as part of a strategic plan. Many of the buildings are unsuitable for the needs of older people and not all are capable of dual registration. This means that older people have to move to nursing homes if their condition deteriorates. This causes a great deal of distress and many older people say they did not consider this before moving in. Anecdotally, it is reported that some homes ask people to move for quite minor nursing needs.

- The other big issue is the shortage of beds for people with challenging behaviour, hence the large number of continuing care beds in hospital existing in Guernsey which have largely been eliminated elsewhere.

- The quality of care varies and regulation is a blunt instrument to manage improvement requirements. Regulation is also vague on levels of social activity to be provided. There are some magnificent homes with high quality care but these should be the norm not the exception.

- Costs vary hugely and not necessarily because of quality of care or accommodation.

- HSSD does not set quality thresholds for paying out of the Long-term Care Fund. HSSD staff are also unable to advise people about their needs as the contract is deemed to be between the older person and the home. Some homes are reported to pick and choose whom they will take and, in consequence, there is a huge shortage of homes for people with challenging behaviour and dementia. Given that many people in homes have dementia the level of dementia training is also reported to be inadequate.

- Many referrals to residential care homes are made during times of crisis. However, interviews with social care professionals reveal that once a crisis passes, often an irrevocable decision has been made for a person to enter into residential care.

- It could be, for example, that a urinary tract infection causes an exacerbation of behaviours associated with dementia. In these circumstances, the individual in

question is often placed in long-term institutional care. When the infection has been treated and the individual reverts to what is considered normal and manageable behaviour, it becomes very difficult to reintegrate such an individual back into the community.

Consultation points/ older peoples accommodation

- Comment focused on the fact that "people often do not realise that having moved into residential care they will probably have to move on to another home to cater for higher care needs as they age".

- The new Island Development Plan[20] is seen as an opportunity to move from the pragmatic use of existing buildings often unsuitable for long-term care to planned redevelopment of purpose-built accommodation.

- Professionals are concerned that homes are not dual registered when the biggest need is nursing for people with challenging behaviour.

- Carers wanted help choosing a suitable home but HSSD are not allowed to. "Social workers can't tell us (relatives) much about the homes as they say they are not allowed to. It's such a worry knowing which care home to go to."

Adults with learning difficulties and mental health

The recent report on accommodation needs for younger adults with learning disabilities and mental health difficulties analyses both the current deficiencies and future needs. This has already been detailed in section five and does not need repeating.

From the consultations the biggest gaps that people see is the lack of age appropriate accommodation. Service users report being inappropriately housed with much older people. The need for more independence and choice was another clear theme. The 15 flats in the new extra care complex for adults with learning difficulties will do much to ease the situation but too much of the other accommodation owned by HSSD is unsuitable and needs replacing.

[20] http://www.gov.gg/planreview

8. Choice, control and support towards the end of life

Essential components

- End of life care planning should be available to people with their families and carers.
- Good palliative care can make a huge difference to a person's the quality of life and the palliative service in Guernsey is rated highly.
- It is good practice to have a care register, which identifies people in the last year of life so that support can be offered. It is often the GP who will have this information.
- Support staff that visit people at home must be well trained in physical and mental health issues.
- Similar training in residential and nursing care homes is required to enable a person to die there instead of going into hospital.

The Guernsey position

- 1 in 2 people die in hospital whatever their wishes but the palliative care team is extremely stretched[21].
- Residential and nursing homes appear to have more unplanned admissions than is necessary, although precise information is difficult to access
- There is no end of life register and GPs are not sharing this information with HSSD.

Key points from the consultation process

The views expressed were very similar from both families and professionals

- Older people with dementia are rarely able to die at home.
- Many older people have sad deaths in hospital.
- Community services are stretched.

[21] HSSD (2014) "Health Profile Guernsey 2010-2012". Available at: http://www.gov.gg/publichealth

Section seven – Conclusions and next steps

Guernsey is capable of making the sea change required to bring the health and care system into line with society's needs. Japan, amongst other countries, has demonstrated that politicians with a clear and bold vision can achieve change[22].

Japan realised that the hospital centric approach was an unsustainable model to care for older people and now they have a universal comprehensive long-term care system based upon the principles of social insurance, needs-based access to care at home, various kinds of services including low level services, respite care, day care and residential/nursing care, much of which did not exist previously. The stimuli they put in place ensured that the private sector in particular responded to the need to develop new and innovative services.

Guernsey can clearly do the same and re-configure the system so that it provides what people need for the future and is more affordable. The whole system needs to make a shift from hospitals and institutional care towards care at home or in supported housing and more self-care. The most difficult but most important and fundamental issues to address are the role of GP, development of community care services and the development of the strategic planning role of the States. These necessities are clearly understood by the many people I interviewed.

The States will not get there in one go and will have to move incrementally towards a shared vision of the whole system but the framework vision will always be the guide.

Returning to the specific questions posed by SLAWS:

- What care, support and supported accommodation services are needed?
- Who should provide them?
- How should they be paid for?

Within the visions of change outlined in this document, and understanding that all information collected to date has come with a health warning about accuracy, we can make some progress and quantify some of the gaps.

On the question of what services are needed, the report discusses gaps in:

- Support to carers.
- Dementia care.
- Supported accommodation particularly for younger adults.
- Supported accommodation choices for older people.

[22] Nuffield Trust (2013) "Caring for an ageing population", Available at: http://www.nuffieldtrust.org.uk/publications/caring-ageing-population-points-consider-reform-japan

- Residential accommodation for people with challenging behaviour.

More work will be needed to provide more accurate need figures.

On the question of who provides, the report

- Emphasises the need to develop the planning role of the States
- Proposes that the States as a provider of services, concentrates on more acute services and works with third sector organisations to provide the lower level but still important services.
- Proposes that the role and capacity of the third sector is developed so that they can partner in some services and /or tender to be providers. In addition there needs to be clear pathways for people to access the services and support provided by the third sector.
- It also suggests that in certain areas the States considers attracting large organisations such as Carers UK and Elderly Accommodation Council to work on the Island.
- In the private sector, there is the opportunity to develop strategy partnerships with private developers to build accommodation. The States resources are stretched and the UK, which has similar financial issues, has gone much further in working with private developers in Public-Private Partnerships.

This stage of the work has not covered finances specifically but some general suggestions and recommendations have been made.

- The States should provide less funding for building works and make more use of the private sector through contractual partnerships.
- Better use of existing resources by focusing on high level services and working more with the third sector.
- Better value for money from residential and nursing homes and an increase in capacity to support people with challenging needs so that the continuing care wards can be closed.

Change does have a cost as there will always be some dual running and authorities have handled this by establishing ring fenced time-limited change budget. However, the current system is unaffordable to the States and some of the population; whilst being very generous to others; so costs will increase regardless.

Next Steps

It is recommended that

- The States carry out a consultation exercise about the big changes that are being recommended if the vision is agreed. This would consist of a summary of the visions and a structured set of questions.

- Use experts by experience, i.e. service users, to comment on how the care components would work for them.

- Begin the corporate process of developing a robust programme of information gathering and information analysis to assess the need for services for the future. This should be managed corporately so that it takes account of the whole system and not just departmental needs. How GPs are to provide information will have to be decided.

- Produce a project plan for developing community care services, which shifts resources from secondary to primary budgets. Approaches might include reviewing the use of the long-term care fund for care at home (at least in the short term to provide the change management resources), using the voluntary sector to provide the low level services, up-skilling the HSSD care staff to provide more intense care packages backed by specialist nurses working in the community, means testing care fairly across the board and stimulating private sector provisions.

- Shifting the balance between institutional care and hospitals would not provide savings overnight and some ring fenced funding would be needed to make the changes, but saving could be expected thereafter.

- Proceed with quick wins.

Quick wins or low cost changes

- Undoubtedly, the most popular, with relatively modest cost implications, would be respite care and carers support.

- Invest in good commissioning skills.

- Invest in developing strategic partnerships and stimulating the third sector service provider market.

- Investigate strategic partnerships with the private and third sectors to provide new accommodation and services with minimal or no grant funding.
- Several mentions were made about the need to finally sort out the equipment store.
- Continue with the plans for regulation ensuring that regulatory developments understand the care and support framework being put in place
- Initiate service level agreements with care homes with clear outcome measures and open up a dialogue with them about providing higher levels of care to people with challenging behaviours.

Appendix one: Definitions

Primary care
Primary care is the first point of contact between individuals and the health system. It brings health services as close as possible to where people live and work, and is, in many cases, the first element of a continuing healthcare process.

Primary care services – generally speaking, services to which people can refer themselves – include GPs, dentists, opticians, pharmacies, some physiotherapists, and some forms of mental health counseling, as well as Accident & Emergency.

Primary care also includes outreach services, such as health visitors, which go out to people rather than waiting for people to come to them.

Secondary care
Secondary care tends to mean healthcare provided by medical specialists and other professionals who do not have first contact with patients. In Guernsey, this includes specialist consultants, hospital-based services – from intensive care, to surgery, to pre-discharge rehabilitation services – most mental health services, and most therapists (physio, occupational, speech and language). It also includes most off-island acute services.

Social or community care

Social or Community Care describes the services and support, which help people to continue to live independently at home.

Assistance is available to support individual personal and practical care needs associated with mental health, learning or physical difficulties, hearing or sight problems, or the challenges associated with getting older.

Each person has different requirements for their care. To continue living in your own home, you may need help with personal care such as washing and dressing. You may also require practical support with daily living such as cleaning or making meals. You may benefit from special equipment or adaptations to your home that will enable you to carry out daily activities.

The range of community care services available to support a person include:

- Personal care, which affects the person such as bathing, dressing, medications
- Domiciliary care (more commonly known as home help)
- Equipment aids and home adaptations (grab rails, hand rails or stair lifts)

- Meals on wheels
- Day care (provided in day centres)
- Respite care (non-residential)

In medicine, **comorbidity** is the presence of one or more additional disorders (or diseases) *co-occurring with* a primary disease or disorder; or the effect of such additional disorders or diseases. The additional disorder may also be a behavioral or mental disorder.

A personal budget is the term given in the UK to the situation where clients are assessed and the cost of their care package determined. This is the amount of money that the client can take as a direct payment to arrange and pay for his or her own care. This can be from an agency, family member or other. The person can spend it as he/she wishes. So for example someone might get their care 5 days a week from an agency, but rely on family at the weekends might use the spare money for an outing. There are also variations on this whereby the client can determine which agency will provide their care and the authority will make a payment directly to the agency on the client's behalf.

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.

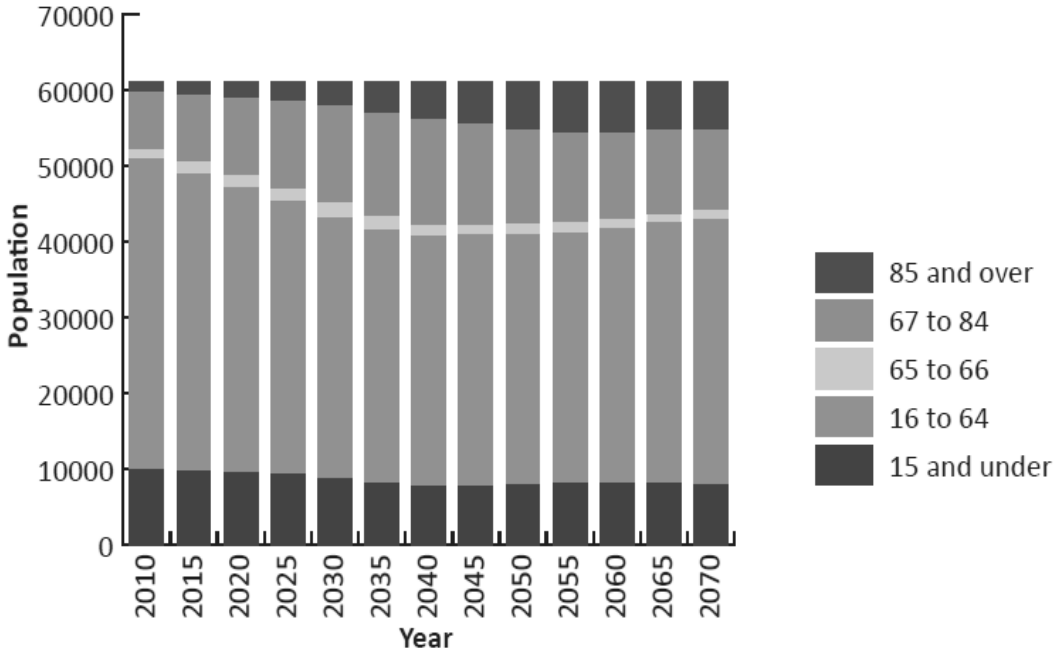
Commissioning has been seen as the opposite approach to micro-managing every detail of the provision or service to be tendered and then relying on price to place the contract. It

encourages innovation, the development of an expert market and provides best information of how the service should perform.

Appendix two – Ageing in Guernsey from the 20:20 Vision

The island's older population is growing steadily. In 2040, as many as 1 in 3 islanders (31%) will be over pensionable age, despite that age increasing from 65 to 67 by 2032. The oldest section of the population, aged 85 and above, could grow from around 2,225 in 2020 to a peak of as many as 6,828 in 2060 – more than 11% of the island's population.

Because the incidence of ill health and disability is, in most cases, closely linked with age, an ageing population will result in a rise in health and social care needs. Recent local research has shown that 1 in 3 people over retirement age have a condition which affects their day-to-day life[23].



In 2009, people aged 65+ formed 15.1% of the island's total population. In 2039, population projections show that people aged 65+ will form 29.6% of the island's total population. An increase of 14.5% in just 30 years. Almost double.

[23] BMG (2013) "Disability Needs Survey: Review of prevalence across Guernsey and Alderney". Available at: http://www.gov.gg/disabilitystrategy

This means that the "dependency ratio" will almost double. That is, currently, there are 100 working age people, paying tax and social insurance contributions, for every 48 people who are under 18 or over retirement age. By 2040, despite the increase in retirement age from 65 to 67, there will be 78 people under 18 or over retirement age, for every 100 people of working age, and the vast majority of this change will be due to the older population.

Thus the demand for health and social care services will increase, while the funding base will shrink. To compound this, new medical treatments and technologies are expected to continue to increase in price at double the rate of inflation (although the value for money of new investments in health services is expected to diminish), which will increase the cost of providing services in the first place.

Similarly, there tends to be a bias towards high-cost, low-value treatments towards the end of life, rather than more effective treatments earlier on. For example, in the UK, it is not uncommon for the NHS to spend £40,000 adding 3 months to the life of a terminally ill person – equal to the total cost of an individual's NHS-provided care over a lifetime, for the majority of people.

The recently published population profile has provided some updates to this[24]:

The recent population projections have provided an update on some figures
The March 2103 figures, published in May 2014, states that the overall population is 62732 and the working population has dropped by 503 persons or 1.2%
The over 65-age group had increased by 263 persons and the population over the age of 85 had increased by 2.5%.

Whilst projections remain robust, the dependency ratio is now expected to be less than previous forecasts because the retirement age will increase from 65 to 67 between 2020 and 2032. Rather than 82:100, the ratio is now expected to be 75:100 by 2017.

[24] Policy Council (2014) "Annual Population Bulletin 2013"

Appendix three: Relevant extracts from the Disability and Inclusion Strategy

Full document available at: www.gov.gg/disabilitystrategy

Objectives -

- Improve opportunities for disabled people and carers to participate across society
- Promote more positive and inclusive attitudes towards disability in the community
- Challenge instances of disadvantage facing disabled islanders and /or carers

Key recommendations

- Information
- Anti-discrimination legislation
- Extend UN convention on the rights of people with disabilities to Guernsey

Through SLAWS to

- Improve the range of independent living opportunities and care and support services available to disabled people.
- Access to long term care and respite care at home and elsewhere
- Improve practical support to carers

Information

- A wide range of relevant easy to access on line information
- Outreach information through targeted media information
- Information and training to staff
- A service to provide regular and update information in accessible formats.
- Budget for someone to keep it up to date and links to relevant advice agencies

The strategy identified 4 groups of disabled people who face multiple and significant disadvantages in the community: -

People with mental health conditions
People with learning disabilities
People with autism and other communication difficulties
People with dementia

3 top priorities identified were: -

Respite care
Carer's plans/assessments
Carers involved in plans for the person.