STATES OF GUERNSEY

THE SUPPORTED LIVING AND AGEING WELL STRATEGY (SLAWS) CONSULTATION

The deadline for submission of responses to this consultation is: 22nd JULY 2015

Instructions on how to respond are provided on the back page of this document

THIS DOCUMENT IS IMPORTANT BECAUSE…

We need your opinions on the long term future of services for people with enduring care and support needs: what services are provided, who provides them and how they are funded. The Supported Living and Ageing Well Strategy will be making recommendations on the best way forward. This consultation is your chance to give your views and provide any relevant evidence, experiences or information for us to consider.

BUT PLEASE UNDERSTAND…

The changes discussed in this document are suggestions under consideration. The Policy Council's SLAWS Working Party has not yet decided what proposals it will recommend be brought forward for the States to debate. Final proposals may differ from the ideas discussed in this document. We will make recommendations only after we hear what you have to say.

CONTENTS

FOREWORD

There is a pressing need to change the way in which our care and support services for adult Islanders (18+) are delivered, organised and funded.

Since 2003 Guernsey has benefited from a Long-term Care Insurance Scheme which has been able to meet the majority of the care and support costs for those who have needed care in a nursing or residential home. Others have their needs met by fully funded Health and Social Services Department (HSSD) services. However, without revision, these services are not financially sustainable in the face of our ageing population.

Of equal importance, the development of this Strategy provides us with an overdue opportunity to review not only how to finance care and support going forward, but also to rethink how care and support are provided - and by whom - to ensure that the right range of services is available from the right organisations to support people to maximise their health and wellbeing.

During the development of this work, we have received valuable advice from Melinda Phillips[1] who came to the Island to meet a range of interested parties in August 2014 and reviewed existing services. We support the direction she has suggested and this document draws on her work.

1
Melinda Phillips, who was previously Chief Executive of Housing 21 - a national not-for-profit organisation providing housing, care and support services - has 25 years of business experience leading substantial not-for-profit organisations. She has also been involved in major government policy development in the UK on housing, ageing and care issues including the 2006 Wanless Social Care Review.

Providing for our population's care and support needs will not be a task for the government to achieve alone – private and third sector[2] organisations have a key part to play as well, not forgetting those Islanders who directly care for and support their family members, who themselves need to be supported. It is important to recognise that this is a joint effort to move the Strategy forward.

Of course, many of you already play an important part in supporting those with care and support needs in our community, and are, therefore, well aware of the benefits and challenges of how current services operate and are funded. Drawing on your valuable experience, we are keen to hear your views so that we can take them into account as we develop the Strategy for the States to consider early in 2016.

We hope that, with your input, we will be able to take the first steps together towards creating a sustainable care and support system for Guernsey.

Deputy Peter Harwood
Chair of the Supported Living and Ageing Well Strategy Working Party

Working Party members:
> Deputy Hunter Adam (Treasury and Resources Department)
> Deputy Sandra James (Social Security Department)
> Deputy Michelle Le Clerc (Health and Social Services Department)
> Deputy Paul Le Pelley (Housing Department)

2 The 'third sector' includes community, voluntary and charity organisations as well as not-for-profit or social enterprise organisations who might be substantial care providers.

INTRODUCTION

The Supported Living and Ageing Well Strategy (SLAWS) aims to address adult (age 18+) Islanders' enduring care, support and supported accommodation needs by looking at the services and funding arrangements provided to them.

This takes into consideration all services and funding provision from those provided to people who are cared for by their families and friends (such as respite care services[3], Severe Disability Benefit and Carers' Allowance); through supported living options, such as extra-care developments and residential and nursing care services; to specialist and hospital care and long-term off-Island placements. The Strategy will also include consideration of services in Alderney.

To prepare this Strategy, in January 2014, a Working Party was put together by the Policy Council's Social Policy Group with Deputy Peter Harwood as chair and political representatives from the Housing, Health and Social Services, Social Security and Treasury and Resources Departments. The SLAWS Working Party will prepare a Policy Letter[4] outlining a framework of what needs to take place for Guernsey to be able to support the needs of its working age and ageing community in the coming years. The intention is that this Policy Letter will be taken to the States in early 2016.

In order to help inform the development of the Strategy an independent expert, Melinda Phillips, was appointed to identify

3
The term 'respite care' is used throughout this document to refer to temporary care arrangements for people who are usually cared for at home by friends and family. It is felt that the term 'respite care' is more widely understood than the alternative 'short-break service'. (N.B. Respite care might be to the benefit of the individual with care needs as well as, or instead of, the carer in any given circumstances.)

4
New term for 'States Report'

changes that need to be made to the current Health and Social Care System. She was selected because of her background, working across housing, health and social care and her understanding of how services need to work in a co-ordinated way.

Melinda met with a number of users of the care and support services as well as health and social-care professionals, carers, and community organisations, and presented her findings and recommendations for improvement in November 2014.

Sections of this consultation document draw on her findings and invite interested parties to comment.

The Working Party believes that effective future provision for all adults (aged 18+) with care and support needs (including disabled people, people with mental health conditions, and older adults with conditions associated with ageing) will need more than an adjustment in funding streams. Instead we need a substantial rethink about care and support services, how these work together and how they deliver the best possible support where and when it is needed.

Consequently, the Supported Living and Ageing Well Strategy sets out to answer three key questions:

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

This document summarises some of the key issues currently under discussion and invites you to comment, share your experiences or provide evidence. This will help to inform the Policy Letter which will go to the States of Guernsey in early 2016. This Policy Letter will outline an overall strategic vision which can be achieved in phases, with some immediate changes and other changes which will take some time to further develop and implement. It is likely that there will be more in-depth consultation on aspects of this Strategy once the direction and principles have been approved by the States.

This consultation document is split into 2 parts:

1. **Part One provides an overview of the existing care services in Guernsey.**
2. **Part Two is a summary of the issues under consideration.**

Issues are thematically discussed in Part Two under the following headings:

> Why do we need a Supported Living and Ageing Well Strategy?
> Change
> The role of the public sector in the provision of care and support services
> A different way to deliver services
> The range of services
> Changing the way we think about care, disability and ageing
> How do we pay?

PART ONE

CARE AND SUPPORT IN GUERNSEY - OVERVIEW

This section is intended to give you a brief overview of what care and support services are currently available.

1 CARE AND SUPPORT IN GUERNSEY

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

We estimate that 2,000 people are receiving care and support from the public sector any time[5]. The Disability Needs Survey undertaken for the Disability and Inclusion Strategy in 2012 estimated that 4,013 people's day to day lives were significantly affected by a long term condition[6]. Some people will only receive help every now and then rather than all year around. Other people with enduring care and support needs are currently being supported by families or private sector services.

For some people changes can be made to their living environment which will reduce the support that they need – for example, if someone who lives in a two storey house finds that they need a wheelchair, then adapted housing might mean that they can continue to live independently.

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

6 BMG (2012) Disability Needs Survey: Review of prevalence across Guernsey and Alderney. Available at: http://www.gov.gg/disabilitystrategy. N.B. this includes some individuals under the age of 16 but it is thought that these individuals do not exceed 500.

WHAT CARE AND SUPPORT SERVICES ARE AVAILABLE AT THE MOMENT?

There are a range of care and support services available in Guernsey, along with some key benefits and financial assistance provided from Social Security, and some provision for housing adaptations. The range spans from services for people with relatively low needs up to services for people with very complex needs. The system is extensive with many relationships between different services and this section cannot aim to cover them all, but rather provides some of the facts about the key services. It should be noted that whilst all of these services are in operation, staffing limitations may restrict the availability and effectiveness of some services at certain times.

Severe Disability Benefit (Social Security)

People who are living in the community (rather than in a care home, hospital or other institutional care setting) who are severely disabled and require help with personal care or who might be at risk if left alone for long periods, can apply for Severe Disability Benefit from Social Security. This is a cash benefit of £98.98 per week (2015 rates), and is available to those with a household income lower than £92,000. In December 2014 there were 611 claimants. This is a non-contributory benefit, which means that it is funded by tax rather than Social Security contributions. If someone is claiming Supplementary Benefit (means tested income support) as well as Severe Disability Benefit, Severe Disability Benefit is not included in assessed income but is paid in addition to any Supplementary Benefit received.

Informal / family care – Carers' Allowance (Social Security)

When an adult has care and support needs it is often their immediate family or closest friends who help them. This can be their spouse/ partner, parent, child or friend. The people who care for their family or friend are referred to as 'informal carers' or just 'carers'. Current estimates suggest that there are between 2,000 and 4,000 carers in Guernsey[7].

Carers of people claiming Severe Disability Benefit can apply for Carers' Allowance if they care for more than 35 hours per week and are over 18. This is a cash allowance of £80.08 per week (2015 rates), and is available to those with a household income lower than £92,000.

In December 2014 there were 417 claimants. This is a non-contributory benefit which means that it is funded by tax rather than Social Security contributions.

If a carer is claiming Supplementary Benefit (means tested income support) as well as Carers' Allowance, then Carers' Allowance is treated as earnings. This means that £30 of Carers' Allowance and any earnings received per week can be received in addition to Supplementary Benefit – but not the full £80.08.

7
The Disability Needs Survey estimated 8% of households (2085 households) contained carers in 2012 (www.gov.gg/disabilitystrategy); In 2014 the Guernsey Healthy Lifestyle Survey (cph.org.uk/wp-content/uploads/2015/01/Guernsey-Healthy-Lifestyle-Report-2014-12th-December-Final.pdf) estimated 5.7% of participants had caring responsibilities (expanded to the whole population this would mean 3,576 people); in 2011 the Housing Needs Survey estimated 15% of households contained people with caring responsibilities – 3,847 households (www.gov.gg/CHttpHandler.ashx?id=79858&p=0). Confirming an exact figure is complicated by the fact many people who care do not define themselves as 'carers' and might see their role as a normal part of family life.

Community Health and Wellbeing Services (Health and Social Services Department (HSSD))

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

> **Social Workers -** Professionals who are available to provide information about services in Guernsey and Alderney and to discuss with people which service may be appropriate for their needs, particularly regarding carer support and help to stay living at home. They call upon a range of expertise to assist with complex problems. They also undertake comprehensive assessments for people who require residential or nursing home care.

> **Senior Carers** - Home care workers who give help with personal care such as washing and dressing, going to the toilet, and provision of simple meals.

> **Carers (formerly home helps)** - Help with domestic jobs such as housework, cleaning, preparing simple meals and emergency shopping. There may be a charge for this service.

> **Community Nurses** - Registered Nurses who have completed a specialised course in Community Health Care Nursing.

> **Occupational Therapists –** Professionals who can assess a person's functional ability to complete activities of daily

living, e.g. washing and dressing or meal preparation. They are able to give advice on appropriate aids and equipment or adaptations in the home to increase an individual's independence.

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

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

> **Shopping Service** – getting in food or provisions for people unable to do their own shopping as a result of illness or being housebound.

> **Sitting service and respite care** - can help carers to have a break from looking after someone at home; day care may be provided for people who live in the community.

> **Transport Service** - mini-buses to help people get to and from Day Centres, HSSD-run residential accommodation, appointments, etc., and also deliver and collect community based equipment. This service is run by HSSD and includes some wheelchair accessible vehicles.

> **Handy person** - gives help around the house for minor home repairs and adjustments. There may be a charge for this service.

> **Meals on Wheels** - deliver cooked meals to those who need and request it. This service is provided by the Guernsey Voluntary Services (GVS) for a nominal charge.

> **Rapid Response Team** - for short-term rapid access to additional support in crisis situations for people or their carers.

> **Health Visitor for Older People** - helps senior members (over 65s) of the community to lead as healthy a life as possible, both physically and mentally, and to improve the quality of their lives by helping them to maintain their independence and keep safe and well in their own home. There is one health visitor for people who are aged 65 years and over. The health visitor's service is free and confidential.

> **Clinical Nurse Specialists** - give advice on issues like pain management, wound care, diabetes, continence and bowel management, heart and breathing problems, cancer care, and mental health.

> **Voluntary Car Service** - helps those who need it with transportation to medical appointments (e.g. an older person living in the community who has an appointment with a General Practitioner or with the Medical Specialist Group). This service is provided by volunteer personnel. It is not wheelchair accessible.

> **Palliative care team** - provides specialist support to people who are close to the end of their lives.

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

In Alderney, nurses from the Mignot Memorial Hospital go out into the community to provide nursing services (injections, changing dressings etc.) as well as some personal care. The States of Alderney in partnership with Age Concern provide some "home help" support to meet other needs (there is also some private provision).

Older Adult Mental Health Services (HSSD)

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

> **A specialist community team** who support those with dementia and Older Adult Mental Health issues. They can provide specialist advice, help with medication and also offer some support for carers who have family or friends with dementia. The team give follow up support to people who have recently been diagnosed with memory problems or dementia.

> **A memory clinic** helps with diagnosis for those with memory problems.

> The **'Sarnia Ward'** which is used for assessment.

> The **Duchess of Kent** (see below).

> The **Lighthouse Wards** (see below, including one ward for complex physical conditions as well as mental health conditions).

> A **day centre** for older people living in the community. This includes people with mental health conditions and people with physical conditions.

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

Adult Disability Services (HSSD)

Disability Services include:

> A multi-disciplinary **community team who specialise in physical disability** – this tends to focus on specialist advice and support for working age adults with physical and sensory disabilities and neurological conditions.

> A multi-disciplinary **community team specialising in learning disabilities**.

> A **Day Centre** based at St Martin's Community Centre supporting people with learning disabilities.

> An **accommodation service** which provides accommodation for over 70 people with learning disabilities and also offers some respite care placements.

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

Disability Services support 128 people[8] who are 'active' on the Learning Disabilities' Register as well as a number of people with physical disabilities via the community team. The services work closely with those third sector organisations that also provide support to disabled people.

8 Figure accurate at November 2014

Mental Health Services (HSSD)

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

Adapted housing and housing adaptations (Housing and Social Security)

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

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

Extra-care housing (GHA, Housing 21, Housing Department and HSSD)

There are three extra care housing developments in Guernsey, providing apartments with an onsite care team and communal facilities (e.g. a café).

> ‘Rosaire Court and Gardens’ which is run by Housing 21, contains 85 flats. Funding is provided for care staff by HSSD.

> ‘La Nouvelle Maritaine’ and ‘Le Grand Courtil’ are GHA properties with care and support provided by staff funded by the Housing Department. The first phase of development saw the completion of 117 flats on these two sites. There is a planned second stage (approved by the States in March 2014) for a further 45 flats on the sites.

Most residents rent their apartments, though the GHA offers some units as partial ownership, and Housing 21 offer some of their apartments for sale. The minimum care requirement for the extra care apartments is a need for 4 hours of care and support per week. The Housing 21 site at Rosaire is for people aged over 55 years, whilst the GHA sites are available for all adults but neither is suitable for families with children.

Residential and Nursing Care Homes (SSD / private and third sectors)

There are 21 care homes in Guernsey and one in Alderney run by the private and third/not-for-profit sectors with 631 beds in Guernsey and 24 in Alderney[9]. If an individual can afford to pay the full fees and wishes to pay the care home directly, they can arrange a placement for themselves without involving the States. However, many people seek financial help from the Long-term Care Insurance Scheme.

9 Figures from internal data on registered beds.

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

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

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

Long term care benefit	Co-payment	Top up fee	Personal expenses
(per week) (from Social Security) • £422.66 (residential) • £556.92 (residential Elderly mental infirmity) • £789.11 (nursing)	£190.75 (per week) This amount has to be paid by the individual. If they receive a full old age pension, this should be affordable within the cost of the pension. If the person has no funds available Supplementary Benefit will often be able to pay the co-payment[10]	Some care homes (but not all) will charge an additional top up fee that the individual has to pay. Top up fees vary from two to three figure sums per week.	Care home residents may also have personal expenses. For example they may need to buy their own toiletries, pay a hairdresser or pay for incontinence pads.

10
We know that Supplementary Benefit currently spends over £500,000 per year to support people in residential and nursing care homes where they cannot afford the Long-term Care Scheme co-payment.

Continuing Care at the Mignot Hospital, Alderney (HSSD)

There is no nursing care home in Alderney, so people who need an equivalent of nursing care are cared for in the Mignot Memorial Hospital continuing care ward. This has 14 beds and over ten years (2004-2013) had an average occupancy of 77%. Whilst the service is mostly funded by HSSD, residents pay a fee equivalent to the Long-term Care co-payment (see section on care homes above).

Duchess of Kent (HSSD)

Associated with the Older Adult Mental Health Service, the Duchess of Kent offers residential placements to cater for older adults with mental health conditions which may mean they need care and support for complex or challenging behaviour. This includes, but is not limited to, dementia. The service is not suitable for those with significant physical or mobility difficulties. There are 26 beds available, 2 of which are reserved for respite care placements. This is where someone comes in temporarily to have a break from living at home or to give the family or friend that cares for them a break or both. This service is running close to capacity. Whilst the service is mostly funded by HSSD, residents pay a fee equivalent to the Long-term Care co-payment (see section on care homes above).

Lighthouse Wards (HSSD)

The Lighthouse Wards (Hanois, Fougere and Casquets) are on the Princess Elizabeth Hospital site and provide specialist residential placements for people with complex physical needs. Their services are not age-specific but are need-led. One ward is specifically focused on complex behaviour associated with mental health conditions (especially dementia), one ward is for people with both complex behaviour and physical needs, and another is solely for complex physical needs. The current capacity is 53 with 2 respite care beds. Average occupancy is high with the service usually running at or near capacity. Whilst the service is mostly funded by HSSD, residents pay a fee equivalent to the Long-term Care co-payment (see section on care homes above).

11
This is the best available estimate. There are complications in identifying a total figure because, particularly for community services, people may claim benefits from Social Security and use several services from HSSD and it is not always possible to identify where one person is using multiple services and avoid double-counting them. Development of data systems is something which will be addressed as part of the Strategy.

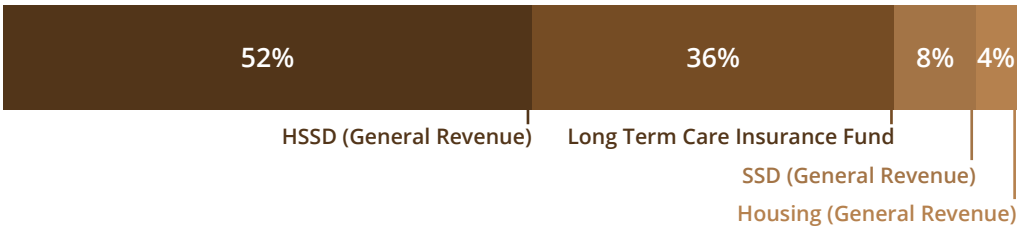
Off-Island placements (HSSD)

People who have complex needs which cannot be catered for adequately on Island can be offered an off-Island placement in a specialist centre in the UK. In 2013 there were 60 adults in placements for complex conditions in the UK.

SUMMARY

Whilst we cannot place a precise figure on the number of people supported since some people use multiple services and there is a risk of double counting, we know that the formal care system supports approximately 2,000 adults[11] at any one time in Guernsey and Alderney (about 3% of the population). In addition, others are being cared for exclusively by their friends and family.

The total cost to the States of providing these services was estimated to have been over £48m[12] in running costs[13] per year. Of the £48m identified, over half the costs are met by HSSD through its General Revenue Budget (i.e. tax income). The Long-term Care Insurance Fund (funded via Social Security contributions) accounts for around 36% of total expenditure. It is, therefore, important to look at the 'whole-system' costs when considering matters of funding.



12 This is largely based on figures from the 2013 Accounts, but for the Housing Department includes the budgeted 2015 operating costs of the extra-care development which became operational in 2014 rather than the Longue Rue House and Maison Maritaine residential care homes which were operational in 2013.

13 This figure includes service and benefit expenditure but not capital costs, transport costs, building maintenance or management overheads which are accounted for separately. Neither does it include any benefits related to living costs such as Supplementary Benefit or Incapacity Benefits.

PART TWO

THE DEBATE

Part Two of this consultation document outlines some of the issues we are facing with our care and support provision and some suggestions for improvements. This should help to support and inform responses to the consultation.

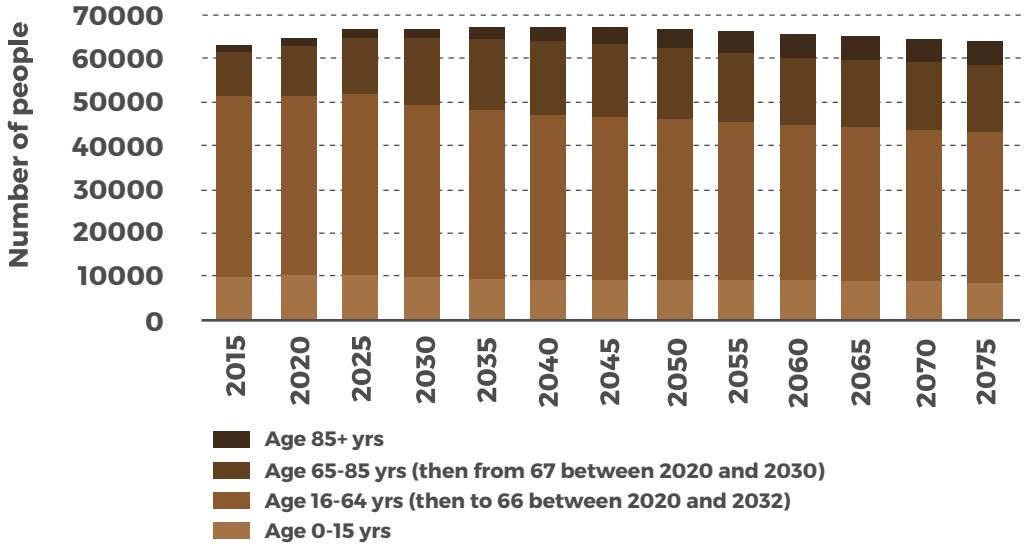
The suggestions in this section are being discussed currently by the Working Party, but decisions will not be made until your responses have been received. Your input can influence the direction the Strategy will take, so it is possible that some of the subjects discussed below will not be proposed to the States in the form outlined below or, indeed, at all.

2 THE DEBATE

SECTION A - WHY DO WE NEED A SUPPORTED LIVING AND AGEING WELL STRATEGY?

Guernsey and Alderney's populations are ageing. In the future a higher proportion of the people living on the Islands will be over retirement age. The number of people over 85 is expected to more than triple by 2050 in Guernsey and there is likely to be a similar or even larger increase in Alderney.

Figure A1 – Projected population in Guernsey by age group

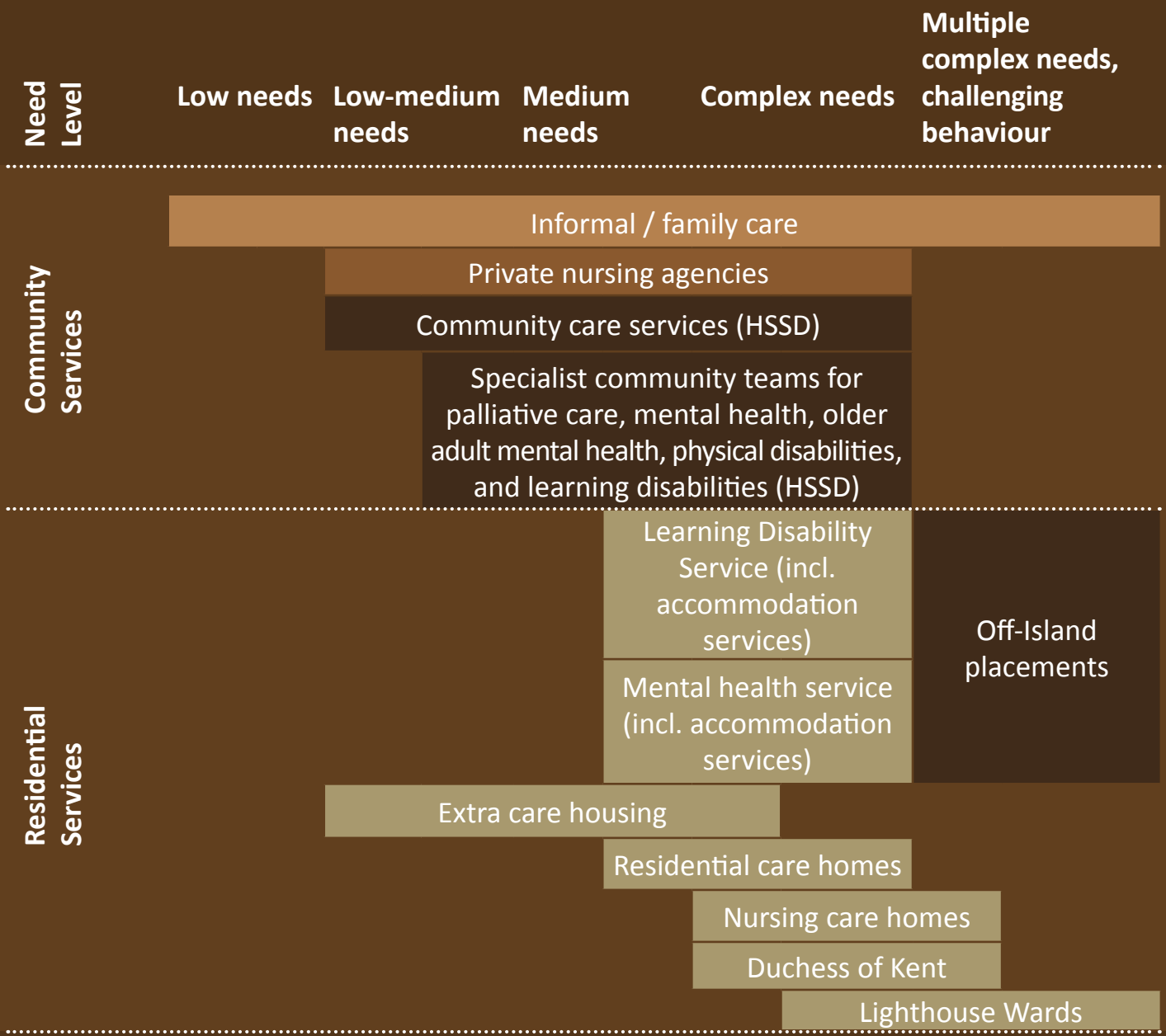


This ageing is partly because significant progress has been made in reducing premature deaths from things such as strokes, cancer and heart diseases. Many people are living longer with these conditions, some developing several conditions simultaneously. 1 in 3 of our older people, for example, who have physical problems will also have mental health issues. Younger adults with conditions which were previously considered life-limiting are also living longer. Services which have been designed to support people with single conditions for a relatively short amount of time need to adapt and work together so that they can support people with multiple conditions for extended periods, and provide enabling environments in which people can live as normal a life as possible whilst exercising independence and choice over how they live.

There are currently a range of services in Guernsey which support people with enduring care and support needs (see Part One for an overview). This can be illustrated by the 'continuum of care' shown in Figure A2. Services range from those supporting people with low needs who mostly take care of themselves, to people with complex or challenging needs who cannot be cared for in Guernsey and are offered specialist residential placements off-Island. In order for this range of services to be experienced as a 'continuum' we need to make sure that there are no gaps in provision and that services work together centring around the person with care needs. Some changes may need to be made to achieve this.

The diagram (right) illustrates that across the range of need levels, there are some services which cater to specific levels of need (for example, off-Island placements are only for people with very complex

Figure A2
The continuum of care


Need Level
Low needs
Low-medium needs
Medium needs
Complex needs
Multiple complex needs, challenging behaviour
Community Services
Informal / family care
Private nursing agencies
Community care services (HSSD)
Specialist community teams for palliative care, mental health, older adult mental health, physical disabilities, and learning disabilities (HSSD)
Residential Services
Learning Disability Service (incl. accommodation services)
Off-Island placements
Mental health service (incl. accommodation services)
Extra care housing
Residential care homes
Nursing care homes
Duchess of Kent
Lighthouse Wards
KEY
Paid for by the States
Paid for by the Individual
States funded with individual contribution
Privately funded, may receive e.g. Carer's Allowance

needs); while other services cater to a wide range of need levels (e.g. community services). People will often move between different services as their needs develop or change.

As a result of our ageing populations the proportion of people on the Islands accessing care and support services is expected to increase whilst the number of people working is expected to decrease. This means that the cost of services will increase whilst the funds available to pay for them will decrease. The system has to change in order to make it financially sustainable. Whilst the Long-term Care Insurance Fund covers less than half of the total cost to the States of care and support services for adults with enduring support needs, Figure A3 illustrates the effect of that increased cost. Funding will not be available in future unless the amount we pay into the Fund via Social Security contributions increases significantly or the way in which care is provided changes.

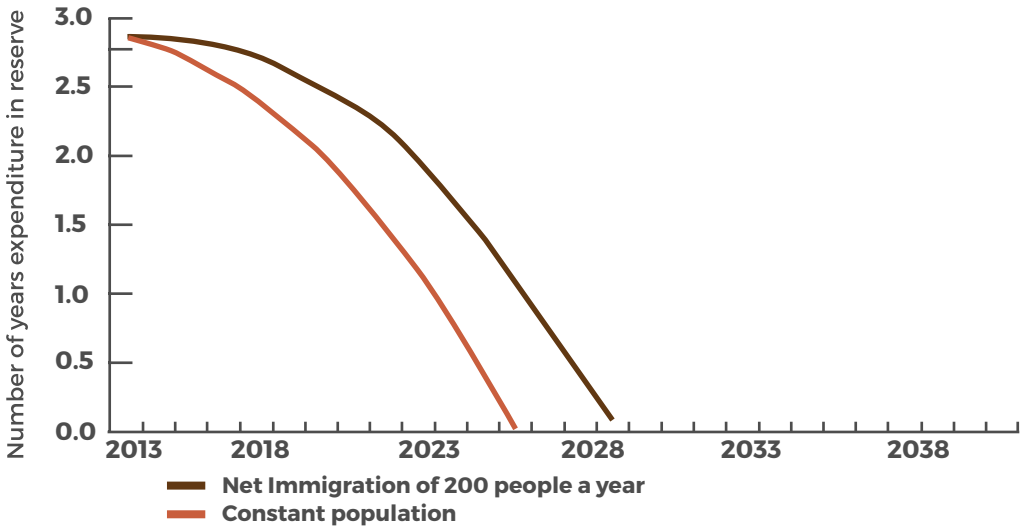


Figure A3
Projection of reserves in the Long-term Care Insurace Fund with current contribution rates maintained

In order to manage care and support provision in this changing environment, we need to develop an overall, agreed strategic direction to ensure that care and support provision is sustainable and that people in the community and the services provided by the private, not-for-profit and public sector work together in an effective person-centred way.

SECTION B - CHANGE

As we have set out in Part Two, Section A of this document, there are a number of reasons why the current system needs to change, including an ageing population and associated funding problems. However the delivery of health and social care is also influenced by the following, which are constantly changing:

> **Societal changes** – changes in social structures can change what care and support is needed and what people's expectations are. For example:

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

- *People are increasingly dispersed* - there may be an increased number of older and disabled adults in future who do not have family living on the Islands.

- *Generational changes* – current and future generations may expect more choice over what care they receive than previous generations.

> **Technological and environmental changes** – changes in technology can influence what care and support is needed. For example:

- *Developments in medical interventions* - that can treat or prevent conditions which are now widespread. For example, if there were ground-breaking and readily available treatment for dementia, the way in which care for people with dementia is planned would need to change.

- *Development of assistive technology* – technology which enables people to navigate disabling environments.

- *Development of telecare and telehealth* – technology which allows people to communicate with health professionals who are in different locations, allows for people to call for help and allows certain warning signs to be monitored remotely.

- *Development of enabling environments* – design of buildings and public spaces so they are more accessible to people with mobility problems or sensory impairments.

The Working Party believes that, rather than seeing the Supported Living and Ageing Well Strategy as a one-off solution to current problems, it will be important for the States to monitor and respond to population, financial, societal and technological changes on an ongoing basis. This will require a commitment to develop our data systems, in order to have readily available, up-to-date data to plan for the future, and to monitor the effectiveness of services and any changes made to their delivery.

Principles to shape change

In order to guide and coordinate change the Working Party is proposing the following principles which will underpin and shape the Strategy going forwards. The Supported Living and Ageing Well Strategy should:

> Promote, improve and protect individuals' 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 that service provision and funding options are sustainable in the medium and long-term.

> Ensure safe, quality care and ensure standards through appropriate regulation.

By pursuing these, the following outcomes should be progressively realised:

a) Reduction, where possible, of the incidence of adults (18+) having enduring care, support or supported accommodation needs by, where possible, preventing needs from arising or increasing.
b) Improved outcomes for all adults (18+) with an enduring care, support or supported accommodation needs.
c) Protection of the health and well-being of the carers of those with care and support needs.

The challenge will be adapting services to align with these principles.

SECTION C - THE ROLE OF THE PUBLIC SECTOR IN THE PROVISION OF CARE AND SUPPORT SERVICES

It is important to be clear about the role of the public sector. This helps members of the public to know what to expect, and helps our third sector and private sector partners to plan their services accordingly to ensure that the range of services needed are available.

Melinda Phillips was engaged by the Working Party in August 2014 to speak to people who use care and support services, their carers, representatives of third sector organisations and health and social care professionals.

Following this review her recommended vision for the future role of the public sector in the provision of health and social care in Guernsey is as follows:

> 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... It will be the centre of service coordination making sure the parts of the health and social care system work well together. Where it is a provider of services, it will use its expertise to focus on acute services and partner with voluntary organisations to provide low level services.

> 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.
>
> 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.

Phillips, M.

In addition to this, the Working Party recognises that:

> the States must strategically manage land use, population and local health and social care training opportunities in such a way that there is sufficient land and staff resources to allow for the growth of supported housing and care services where required.

> the States must also work in partnership with, and support, people who care for family members or friends. More on this is included in Section E.

> the States must seek to ensure that people are able to access appropriately accessible housing options or have resources to adapt their houses where this is the best solution.

The following findings about the current situation were reported:

1. There must be better analysis and planning of needs and services and this is a key strategic role for the States.

- Forward planning is lacking in Guernsey 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.

- 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.

- 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.

2. Information for the public is limited and difficult to access. Only when the States takes on a central planning and analysis function will there be real improvement in public information about services.

- Providing choices to people 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 Citizen's Advice Bureau provided an analysis of the last 111 enquiries and 80 were about social care and health services.

- 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 needs better information that is accessible.

- Without good information/data, 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.

- In conducting this piece of work we found that information quality and records were variable across the services. Recording is done in different forms and mainly for internal use not strategic collection and planning.

3. **There is an ambivalent attitude towards the private sector and towards the third sector and both can be used to better effect. However, this must be part of a planned approach to analysis and identification of service needs which are communicated well so that these sectors can respond.**

- The States is also unclear about which services it wants to directly provide and which it wants to outsource. 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.

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

- The private sector is a significant provider in Guernsey but it is felt by many that parts of it… are not sufficiently 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 providers. 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 able to take people with complex care needs… 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.

- Given the appetite for supported housing such as extra care housing, the States would benefit from looking more to the private sector to provide it. [Internal research carried out in 2010 identified] 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.'

Phillips, M.

SUMMARY

Consequently, available evidence suggests that the States needs to develop a strategic planning role which would involve:

> Monitoring the number of people in need of care and support, the availability of care and support services, the quality and safety of care, and people's satisfaction with the care and support they receive.

> Actively supporting the development of appropriate services where there are not enough existing or where there are problems with safety or quality.

> Coordinating care across the private, public and third sectors, and making sure that referrals and links between services work effectively.

> Ensuring information is available so that people can find support when they need it and make informed choices.

> Broadening and developing regulation of all services within the care sector.

> Preventing needs from increasing through health promotion and the promotion of positive attitudes towards disabled people and towards ageing.

> Ensuring strategic management of population, land and education to support growth in the care sector where needed.

> Ensuring that, where possible, the housing stock is built to accessible standards and that there is support to adapt housing to make it more accessible, where this is the best available option.

In terms of service provision it is suggested that the States, in the long-term, should focus on more specialised services and that more general services should be provided by third sector or private sector organisations as their capacity to provide services develops.

SECTION D – A DIFFERENT WAY TO DELIVER SERVICES

This section looks at the structure of services in Guernsey and the way in which they are delivered. As outlined in the principles (see Section B), the Working Party aims to ensure that the system is integrated in such a way that it is centred around the person with care or support needs, so that they have opportunities for choice and so that ways of working are seamless and support their wellbeing.

The vision of a system of health and social care provision is as follows:

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.

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

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 [or in a long-stay hospital ward].

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 in 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 care and advocacy to support them to continue caring…

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 often contrary to their wishes…

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.

Phillips, M.

The Working Party believes that in addition to Primary Care services, the local community themselves must be an integral part of the foundation for a new system of care and support. As well as the important role of carers and community and not-for-profit organisations, the support which individual Islanders can provide

in their day-to-day encounters on the bus, in shops and in their local neighbourhoods is important in making the Island a better place to live (see for example, work in the UK on Dementia Friendly Communities[14]).

14
e.g. alzscot.org/dementia_friendly_communities

Three elements have been identified as priorities to realising this vision by changing the way services are delivered:

1. Where delivering multiple services to an individual, services must be coordinated.
2. Provision should move to being more community based and the gap between the hospital and home should be blurred.
3. The GP services must be better linked into the rest of the health and social care system.

1. Delivering multiple services in a coordinated person centred way

There is a need to link services together in a more coordinated way:

We need to move away from looking at the quality of services individually and look at the way the whole system supports us at different stages in our lives. We often need several services at the same time and we need good transitions between hospital and home with services that follow us. We want to feel in control of the choices we make and to be provided with information so we can make informed choices.

So 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 we need to live well at different times of our lives. These components of care should be regularly "walked through" by users and providers to ensure they continue to offer what we need.

Phillips, M.

In her discussions with people with care and support needs, community and third sector organisations, and health and social care professionals, Melinda Phillips discusses "Can the system support and provide the following?"[15]

> Help to maintain healthy, active ageing and independence.

> Support to live well with simple or stable long-term conditions at home.

> Support to live well with complex and multiple conditions, dementia and frailty, both at home and in a home [or long-stay hospital ward].

> Rapid support close to home in time of crisis and good rehabilitation and re-enablement after acute illness or injury.

> Good hospital and specialist care when needed.

> Good discharge planning and post discharge support.

15
Based on the Kings Fund (2014) "Making our health and care systems fit for an ageing population". Available at: kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf [accessed 15th June 2015].

> 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.

Her findings on this area are as follows:

Whether we are living in a home or at home, ageing and better treatments mean we may need several services at the same time not just one at a time. There is significant evidence that in Guernsey, as elsewhere, people struggle when they need several services to be co-ordinated. This is particularly true for anyone with a physical as well as mental health needs such as a frail older person who also has dementia. There is a big challenge to improve diagnosis, treatment and support for people with mental health problems and to connect physical and mental health services.

Co-ordination across services in Guernsey is difficult because the foundations of shared data and single assessments are not in place…

At a strategic level [provision of] States Services are also complicated and sometimes ambiguous. Whilst HSSD is responsible for policy and regulation it is not always the paymaster and SSD [the Social Security Department] sets policy through payment decisions. SSD also contracts with MSG [Medical Specialist Group] and GPG [Guernsey Physiotherapy Group], 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 [specialist care which GPs can refer people on to] is largely free. People therefore use secondary care whenever possible, which is expensive when their conditions could be managed in the community by GPs.

At a practical level, services can be fragmented and operate in isolation particularly across mental health and physical health… The following excerpt is from [research conducted in 2010]:

> 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 Older Adult 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 Older Adult 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 [research also reported] 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.
>
> 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 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.

Roughly a third of people in the UK 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.) As an example of where this might be a problem: in many countries dementia training is standard across all services that work with older people. However in Guernsey, 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.

Phillips, M.

2. Rebalancing provision between hospital and institutional care and home based care and providing more community based services

The need to provide more community services and to make transitions between hospital and home based care more straightforward have been highlighted:

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. In Guernsey community care services are underdeveloped and cannot support enough people to continue to live in their own home...

Regular transitions between hospital and home is also not something that most Western systems was developed to deal with. There can be big gaps between primary and secondary care services so people often have difficulties as they move from hospital to home at a time when they most need help to make a full recovery and regain independence.

Findings

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[16] and not primary care and this has created some barriers. Japan, for example, has made substantial changes to its overall integrated care approach

16
Whilst the Primary Care Mental Health and Wellbeing Service for 18-65 year olds is now available, it does still require referral from a GP.

through providers who offer multi-disciplinary hospital acute services and community services which follow the person out of hospital.

Guernsey needs to shift the balance… [from hospital or institution based care to care in the community]. A hospital [or institution] centric system will not be affordable in the future and it is not what people want. People require a choice of care, where that care is provided and the options should be on an unbiased financial footing.

The long-term care insurance whilst admirable in conception, only offers payments to people moving into private nursing and residential homes…

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 for long periods 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 often not what people want.

However 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.

Phillips, M.

3. Integrating the GP service into the whole system

The role of GPs has been identified as playing a crucial role in the system as a whole:

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 dual 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”. 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.

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

is critical to the whole system working well and this is a problem for Guernsey to address…

The GP system in Guernsey works in a less integrated way than in many other countries. GP's 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. GP's 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...

Nevertheless, the GP service in Guernsey is well placed to fulfil this dual role - supporting individuals as well as the health of the local population. 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.

Phillips, M.

The role of GPs is undoubtedly important to the whole system. However, the Working Party is exploring whether GPs or other primary care professionals are best placed to provide the key primary care coordination foundation for social care and support services.

SUMMARY

There is a need for Guernsey to develop a more person-centred system of care and support. The following components have been identified as key to delivering such a system:

> A primary care foundation which is involved in coordinating care, signposting and ongoing support of patients.

> Flexible services which follow people and can support people both in hospital and at home when they leave hospital, as well as developed community services.

> Greater integration of mental and physical health services (also discussed in Section E).

> A coordinated system of services working together (also discussed in Section C) and using single assessments (as well as separate assessments for carers).

> A system which supports choice and where the services and funding available do not unnecessarily restrict people's choices (also discussed in Section G), including choices about where people wish to die at the end of their life.

Section E – The range of services and support

As well as considering the structure of services and how they work together, we also need to consider the range of services available and whether there are gaps where needs are not met. Four service gaps have been highlighted as being priorities for action. These are:

1. The need to develop adult mental health and dementia services.
2. The need to develop support for people who care for their family members or friends (informal carers).
3. The need for more respite care provision (services which care for someone on a temporary basis whilst their family carer has a break or attends to other responsibilities).
4. Gaps in the provision of 'housing with care' (which covers care homes but also other supported housing contexts with onsite staff, like extra-care housing).

Gap 1. The need to develop adult mental health and dementia services

Whilst some work is progressing as part of the Mental Health and Wellbeing Strategy[17], there is a significant need to plan for an increasing incidence of dementia as the population ages and there are more people over the age of 85 (see the figure A1 on page 26). A number of issues relating to dementia have been identified, including the following:

17 Agreed by the States in 2013 – see gov.gg/mental-healthandwellbeing

> There is a need to increase professional knowledge and understanding of dementia to increase the opportunity for early and effective diagnosis.

> 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).

> Carers without information or support to understand dementia.

> Very limited good residential and nursing dementia care available in the privately run homes, hence the very large number of beds on the Lighthouse Wards.

> The lack of availability of beds in care homes for older people with dementia.

Phillips, M.

The UK National Dementia Strategy (which informed the Guernsey Mental Health and Wellbeing Strategy) and other international examples could be used to focus service developments.

The strategic objectives of the National Dementia Strategy [Living well with Dementia, Department of Health, 2009] are:

> 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

There is increasing good practice around the world, which Guernsey can benefit from. For example in Germany, they have put more 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 and dance. Germany is trying to change attitudes towards dementia and ensuring that people with dementia participate in what makes the rest of us happy - focusing on the positives.

Phillips, M.

Gap 2. Support to carers

We need to increase support to carers:

Supporting carers can be as important as supporting the person [who has care and support needs] since so much of our social care is provided by families and friends. However to continue to carry out this role carers need services too:

> 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."

Phillips, M.

There are a number of areas where carers needed further support in Guernsey:

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 others, 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.

An assessment. Carers need their own assessments, which would identify the support they need to continue caring. This is being piloted at the moment.

Training. Particularly about dementia. Carers need to know more about the disease and how it will progress so that they have coping strategies.

Information. The Disability and Inclusion Strategy states that there needs to be "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. 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 carers' allowance. Many of the moves by couples into residential and nursing care seemed to happen when the carer also becomes ill. Families say they need information about the suitability of different care homes.

Respite care. This would allow carers a break from a difficult task. ***Phillips, M.***

Gap 3. More respite care is needed.

Linked to the need to increase support to carers, there are currently several types of respite care but all of them seem to have shortages and more respite care is needed:

> Guernsey does offer a sitting service run by HSSD. [This service provides a professional carer to sit with the person with care and support needs for a few hours or at night whilst the carer attends an appointment, socialises, sleeps, takes a break or has some time to themselves.] … this needs to be booked some time in advance as availability is limited.

> The number of respite care beds is too small to satisfy the need. The Needs Assessment Panel (NAP) authorises payment for respite care and issues certificates. In the first 6 months of [2014] NAP… noted a shortfall of 26 respite placements… This is in addition to the many people who either do not [know respite is an option or] do not ask for respite care because they know it will be unavailable. All professionals who took part in the review were concerned about the lack of respite help available and what was available was usually for an emergency only.

Phillips, M.

Gap 4. Gaps in the provision of housing with care.

'Housing with care' refers to different kinds of housing where there is some on-site staff support. This incorporates supported housing like extra-care flats where people have their own apartments but there are staff providing care or support to the apartment block, or residential care homes where residents live in their own room but share communal areas with staff supporting all residents. There are gaps in provision both for younger disabled people and for older people.

Adults with physical disabilities, learning disabilities and mental health conditions

Melinda Phillips highlighted that "the supported housing options for younger adults with learning difficulties, mental health difficulties and physical disabilities are very poor." There is only one (third sector) care home which caters to physical disabilities and some

extra-care flats available. In some cases younger physically disabled adults have been inappropriately placed in nursing homes which cater mostly to older people due to the lack of options available. There is, however, currently accommodation provided for people with learning disabilities and mental health conditions by HSSD. However:

> 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… 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.[18]

18
These adults are now accommodated in the extra-care schemes at Le Grand Courtil and La Nouvelle Maritaine.

Phillips, M.

Older people

The findings in respect of older people are as follows:

> It is difficult to be precise about the needs because the States has not developed its planning role. However Guernsey will have circa 530 flats in sheltered and extra care

accommodation when the new developments are complete. 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.

> …in the UK… 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 [in Guernsey] 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.

> Demand for extra care housing in the Guernsey has been 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 apartments 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.

> 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. In the UK, it is very rare to find individuals being cared for in continuing care hospital wards [Lighthouse Wards]– these individuals are more appropriately placed in nursing homes and hospital is reserved for illness and acute medical needs. There are still 77 continuing care beds in hospitals in Guernsey

Phillips, M.

Other gaps

The Working Party has identified other gaps in services which will need to be met in order to deliver the Strategy. These include:

> Underdevelopment of adult safeguarding – agencies who work with adults with care and support needs should work together to ensure that the risk of abuse or neglect is minimised and concerns are addressed. Development of safeguarding is already underway as part of the Disability and Inclusion Strategy.

> The need for supported employment to ensure that people with disabilities have opportunities to work, which has been

enhanced by the recent establishment of the Guernsey Employment Trust . This is a key part of the Disability and Inclusion Strategy which was agreed in 2013.

> There are issues regarding the provision and funding of aids and adaptations to support people to live independently. This includes underdevelopment in the provision of technological aids under the umbrella of telecare services. These can include a range of devices which can support carers or community teams; for example, sensors which alert carers when someone with dementia has left their house unexpectedly.

Issues of Quality and Effectiveness

Whilst most of this section has focused on the types or quantity of services available, it is also important to ensure that the services that are delivered are achieving the desired outcomes and are of an appropriate quality. The current practice for some unrelated adults to share bedrooms in residential homes, for example, runs counter to some of the principles of the Strategy outlined earlier in this document.

Section F - Changing the way we think about care, disability and ageing

To some extent expectations shape the way in which we, as a society, approach care, disability and ageing. Arguably, part of the role of a Supported Living and Ageing Well Strategy should be to challenge some of the unhelpful 'norms' and stereotypes which could restrict people's options and expectations.

For example, there is a danger in expecting too little from care – from expecting it only to be enough to keep a person warm, safe and fed without aspiring to help them to live in a way which is meaningful to them. Sometimes it might seem easier to do something for someone (e.g. make a cup of tea or go shopping) than to help them to do it, or participate in doing it, themselves – even if they would value this. Realising this kind of aspiration depends on cultural changes amongst care staff so that value is placed on enabling and assisting as a default.

Whilst meaningful activity is important for everyone, younger disabled adults in particular may also need support to participate in some of the fundamentals of working-age life, such as working or raising children. Some work is underway in the Disability and Inclusion Strategy to improve employment services and opportunities available to disabled people. The other needs of working-age disabled adults need further consideration.

There are also dangers in stereotyping people with care and support needs – by suggesting that they are a 'burden', cannot contribute

to society, shouldn't expect to be able to leave their residential care or participate in society, that they should be grateful for what services they receive. If people with care needs living on their own in the community are isolated or people in care homes are not expected to be interested in, for example, doing exercise, going out to town or using the internet, then there is a risk services will not be provided to them which could support their mental and physical health.

Some care services in Guernsey do support people to pursue wider interests and participate in society. From the discussions undertaken in developing this Strategy, we sense that it is felt others could do more to support people to do what is important to them. Additional staff training might be one way to support this goal.

Associated with these discussions are concerns about ageism and discrimination against people with disabilities. This might, for example, be in the form of opinions about what kinds of activity are appropriate for a person of a certain age or a person with disabilities, or opinions about what relationships they should or shouldn't form. The Disability and Inclusion Strategy is already undertaking work to address discrimination against disabled people. Ageism, however, is not currently being addressed.

The Working Party is considering highlighting the need for work to be undertaken on ageism and the promotion of a person-centred, enabling culture of care in its Policy Letter.

People may experience discrimination when receiving care and support on other grounds than of their age or disability. For example, it is possible that in some cases married heterosexual couples might be given certain rights to live together or visit each other which are not given to homosexual couples. The Working Party recognises that it is important that everyone receives the care that they need in a non-discriminatory environment no matter what their age, disability, gender identity, sexuality, or ethnicity and that discrimination is taken seriously and addressed within all private, public and third sector care and support services.

Section G – How do we pay for care and support?

Providing care and support can be very expensive. Increasingly, more people are living many years with complex and multiple health conditions, and as people develop multiple long-term conditions so the costs of their care and support increases[19]. At the same time:

"Our community is changing – the balance between the number of people who are of working age and the number of people who are not is shifting. The way that we fund and deliver public services needs to adapt if it is to be sustainable in the long-term. If it doesn't the time is fast approaching when the States will struggle to provide essential public services and support those in greatest need."[20]

In order to make the future provision of care and support sustainable, the Strategy needs to incorporate ideas about funding. Whilst some of these will undoubtedly be controversial, it is critical that we find a sustainable way to make sure everyone can receive the care and support that they need.

Current costs

Figure G1 (on page 73) provides an overview of the current costs to the States of providing long-term care services.

The majority of HSSD provided services are free at point of delivery, which means that they are funded entirely from General Revenue

19
For example: Schwartz, M; Iezzoni, L.I; Moskowitz, M.A; Ash, A.S; and Sawitz,E. (1996) "The Importance of Comorbidities in Explaining Differences in Patient Costs", Medical Care, 34(8), pp. 767-782.
Also: Department of Health (2014) "Comorbidities: a framework of principles for system-wide action". [Online]. Available at: gov.uk/government/uploads/system/uploads/attachment_data/file/307143/Comorbidities_framework.pdf [accessed 19th May 2015]

20
Social Security and Treasury and Resources Departments (2014) "Personal Tax, Pensions and Benefits Review" booklet – [Online]. Available at: http://www.gov.gg/CHttpHandler.ashx?id=88878&p=0 [accessed 8th May 2015].

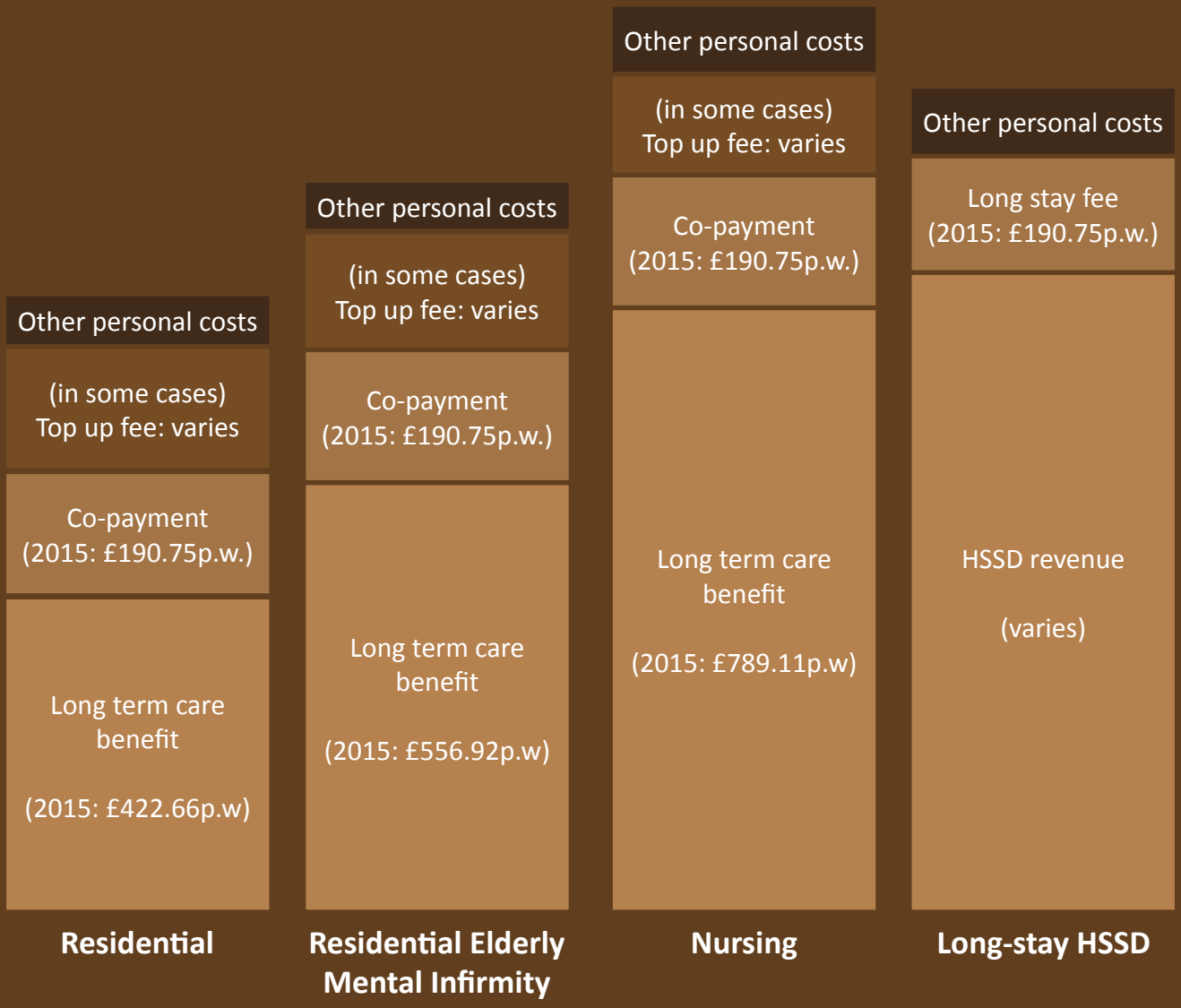
(i.e. tax). For people in institutional care – residential or nursing care homes or long-stay hospital beds – the payment of these costs are shared between the States and the individual receiving care. The diagram on the following page (Figure G1) shows how these costs are shared and the source of funding involved.

Under this system the annual cost to the States per annum is approximately £41,000 for a private nursing home or approximately £22,000 for a residential care home. Per annum costs for people living in HSSD residential placements (including, for example, Learning Disability Accommodation (which has alternative charges to the 'long-stay fee'), Duchess of Kent and Lighthouse Wards) are harder to estimate[21], but are generally more expensive reflecting the high intensity of care in some of these settings. Estimated costs to the States for the average service user range from about £42,000 per annum to around £53,000 per annum.

In both private and States-provided homes individuals themselves will also be contributing almost £10,000 per annum (assuming they can pay the co-payment in full) and, in some private sector homes, also a top-up fee, the amount of which varies from one home to another.

Assuming that the funding system remains unchanged, the States will be unable to meet its share of these costs in the future, given the increasing numbers of people that are predicted to require these services; and this is before the increased cost of providing community services is taken into account.

21
These estimates are based on 2013 accounts data and information on beds available and occupancy. They do not include senior manager, capital or building maintenance costs.


Other personal costs
(in some cases)
Top up fee: varies
Co-payment
(2015: £190.75p.w.)
Long term care
benefit
(2015: £422.66p.w)
Residential
Other personal costs
(in some cases)
Top up fee: varies
Co-payment
(2015: £190.75p.w.)
Long term care
benefit
(2015: £556.92p.w)
Residential Elderly
Mental Infirmity
Other personal costs
(in some cases)
Top up fee: varies
Co-payment
(2015: £190.75p.w.)
Long term care
benefit
(2015: £789.11p.w)
Nursing
Other personal costs
Long stay fee
(2015: £190.75p.w.)
HSSD revenue
(varies)
Long-stay HSSD

This section provides an overview of some of the changes that the Working Party is considering in order to develop a more sustainable funding system in the long-term.

There are essentially three ways in which the needs of an increased number of people can be funded:

> Reducing the cost of care delivery (e.g. through prevention of needs escalating or technological innovation);

> Increasing the level of public funds available by raising taxes or increasing Social Security contributions; and/or

> Increasing the amount of money care recipients or others contribute towards the cost of care (where they can afford to do so).

It is the Working Party's initial view that meeting the population challenges we are expecting and experiencing is likely to require a combination of all of the above approaches.

In addition, any changes in funding arrangements are likely to affect the way in which people approach care and also what forms of care are provided. Consequently, the funding structure is also important because of what it means for people's choices about their health and wellbeing. A number of topics are considered below which will provide a framework to further explore this area.

Figure G1
Paying care costs under the current system

> Reducing costs
  - Prevention
  - Re-enablement
  - Independent living
  - Innovation

> Increasing the available public funding

> Increasing the amount care recipients or others contribute towards the care system
  - Breaking costs down into living, accommodation and care costs
  - Who is responsible for paying for care?
  - Capping care costs
  - Including assets in means testing
  - Availability of affordable care placements
  - Eligibility and access to care

> Other strategic issues related to funding
  - Personalisation of funding systems
  - Compensating informal carers
  - Additional costs associated with living with a disability
  - Working with the third sector to make the most of their resources

i. Reducing costs

Whilst there is no 'silver bullet' to reduce costs, there may be ways to help to keep costs down in the long-term. Some of these may require some initial investment.

Prevention

Some care needs are preventable – for example needs arising from conditions associated with certain lifestyle choices (smoking, diet, exercise etc.). As outlined above, prevention is desirable for both its wellbeing outcomes as well as cost reduction. Ensuring that people have opportunities to exercise, maintain an active mind and eat healthily (and that these opportunities aren't limited by expectations about what disabled or older people should or shouldn't do) can help to stop conditions developing or getting worse quickly.

Re-enablement

Sometimes after a crisis or hospital admission, or due to the development of a long-term condition, someone may struggle to carry out the tasks they once took for granted. Investment in occupational therapy or physiotherapy to support people to find ways to carry out day to day tasks and live more independently after a crisis (e.g. a spinal injury or stroke) can reduce the amount of ongoing care that they need. If people are not provided with therapy they can end up in nursing care and never be given the opportunity to re-gain the abilities they once had. This has quality of life implications and could also be very expensive compared to the cost of early investment in re-enablement therapy.

Independent living

Many people with care and support needs wish to continue living in the community and manage their own home. However, it is important that people living independently in the community

receive all the support they need, and have opportunities to socialise and avoid loneliness.

Providing the right type of support and appropriately adapted or designed housing to help people live independently can reduce the amount of staff time needed to support individuals on an ongoing basis. Some people may need housing which is adapted to allow them to care for themselves, others might need help or support; for example, to learn to cook or manage finances where this was previously done for them by a family member or someone else on their behalf.

Innovation
It is possible that some innovations in the ways of delivering care and support could make them less costly. 'Telecare' technology, for example, could be used to remind people to take medicine or to alert a carer if someone with dementia leaves their house unexpectedly. This might reduce the amount of time a carer needs to be present for an individual to be safe.

Summary
Whilst the above methods of reducing cost will not remove the problem of increasing costs, they could help manage the issues associated with an ageing population and contribute towards containing expenditure. Short-term investment in developing these services may have significant long-term returns.

ii. Increasing the available funding

Whilst efforts might be made to help people to live independently and reduce the levels of care needs in the community, it is likely that there will still be an increased cost because there will be a higher proportion of people on the Islands with care and support needs. Public sector services and funding currently come from two main sources:

> general taxation (largely income tax) and
> Social Security contributions;

An obvious but not uncontroversial option would be to increase tax or contribution rates to increase the funding available to provide services or benefits to people with care and support needs.

In order to identify just how much money will be needed in future, and how many people will have care needs, some modelling work will need to be undertaken. Whilst some initial work is being done to identify the data and variables needed in such a model, we do not currently know what increase would be needed. The Social Security Department has previously identified that in order to make the current Long-term Care Insurance Scheme viable Social Security contributions would need to be increased to around 2 or 3% of earnings: an increase on the current rate from 1.3%[22]. However, as explained in Part One of this consultation document, the coverage of this Scheme represents less than half of the total costs of care and support services at present. It also does not account for the fact that the proposed Strategy may recommend

22 Social Security Department (2014) Benefit and Contribution Rates for 2015, Billet d'Etat XXI. [Online]. Available at: http://www.gov.gg/CHttpHandler.ashx-?id=92398&p=0 [accessed 8th May 2015].

changes to the coverage of the Scheme to change the current balance between residential and nursing care services and the provision of community care services.

If, once the future costs have been projected, we know that we need to increase the amount of funding available, an appropriate increase in Social Security contributions is the most likely way for this to be achieved. However, in line with the Personal Taxation, Pensions and Benefits Review[23], the increase in tax or Social Security contributions will be limited by the 'fiscal framework' which sets a policy limit on the total amount of taxation and contributions the States should raise: that the total of income tax and contributions should be no more than 28% of GDP. This may limit what the States can afford to provide in terms of the ideal mix of care and support services.

23
Treasury and Resources (2015) "Planning a Sustainable Future – the Personal Tax, Pensions and Benefits Review, Billet IV. [Online]. Available at: http://www.gov.gg/CHttpHandler.ashx?id=94029&p=0 [accessed 8th May 2015].

iii. Increasing the amount of money care recipients or others contribute

Based on the above review and the previous public consultations that preceded it, increasing taxes or contributions are not a favoured way forward (and in any case are limited by the 'fiscal framework' as outlined above). However, significantly reducing the cost of care may also not be possible.

This means that it is very likely that some care recipients will need to contribute more than they do at present towards the cost of their care in order to ensure that States' funding is

available for those most in need who have insufficient resources to contribute at the necessary level.

Who is responsible for paying for care?
In most countries care costs are balanced between the individual with care needs, where they can afford to contribute, and the state.

Care needs are unpredictable and hard to plan for. Anyone could develop care needs at any age and the cost can be huge. In particular people who have, or develop, care needs as young adults may not be in a position to be able to pay for their care. In contemporary society there is an expectation that we all have a social responsibility to make sure that people are cared for. There is, consequently, a good case for pooling some resources to share the financial risk.

It could be argued, at the other extreme, that the state should cover all of the costs of someone with care needs as part of its social responsibility. There may be some cases, however, where people struggling with their own living costs are being asked to pay to fund the care of someone quite able to fund themselves. This can raise questions of fairness. There is, therefore, a debate to be had about what balance there should be between the relative contributions of the individual and the state.

There can also be varying views on the responsibilities of family members towards paying care costs. In Germany, for example, parents can legally sue their children to cover the cost of their care. It is thought that this would be culturally inappropriate in Guernsey. Whilst family members may provide informal care and support or

may voluntarily contribute it is felt that Islanders should not be legally forced to contribute to the care costs of a family member (though a spouse/partner may be expected to contribute).

If, then, the responsibility lies between the individual and the state, who should pay what?

Breaking costs down into living, accommodation and care costs
In Guernsey and Alderney, we have been accustomed to all inclusive charges being levied for residential and nursing home care. However, the care cost of residential and nursing home care could be broken down into separate components; namely:

> Living costs (e.g. food, clothes)
> Accommodation costs (e.g. rent)
> Care costs (e.g. the wages of a professional carer)

Indeed, if you live in your own home or in extra-care housing then responsibility for paying for these costs is likely already delineated along these lines.

This kind of breakdown of costs is used by many different countries across the world in order to assign responsibility for payment between the recipient of long-term care and the contribution of the state. If this were to be applied in Guernsey some careful thought and further consultation would need to be given as to what falls into each category. In principle, living and accommodation costs are common to everyone in the Islands and, therefore, regardless of the place where care and support is provided (whether in your

own home, in extra-care housing or in a care home) all adults could be expected to pay these if they could afford to do so.

In reality, the existing co-payment and long-stay fees paid by people living in care homes, the Duchess of Kent, the Lighthouse Wards and the Mignot Memorial Hospital Continuing Care Ward, are thought to be lower than the cost needed to cover, for example, their housing, food and utilities. It could be argued, therefore, that the co-payment should be increased so that (just as if they were continuing to live in their own home) people should pay the full cost of their accommodation and living costs, allowing care costs to be considered and funded separately. To provide a safety net under such a system those who could not afford to pay their living or accommodation costs would be able to apply for means-tested support from Supplementary Benefit.

If such a system were implemented, the costs of care associated with living in the community and the cost of care associated with living in a residential care home would be more comparable. This care element would relate directly to the level of care and support someone needed.

At present there is a divide between how people think of being ‘at home’ and being ‘in a home’ (or in a long-stay hospital ward). It may be possible to begin to blur that distinction, making care more available in the community and making ‘care homes’ feel more like being ‘at home’. Making the funding systems more comparable may go some way in achieving this.

Capping care costs

Implicit in the above is that the States should pay care and support costs in full. However, many countries are finding that they are unable to afford to pay for all of their care costs. To protect people who have substantial ongoing costs and those who do not have resources to pay for care, some governments have established thresholds to establish the parameters for state funding. Typically these take the form of:

> A lower threshold, under which people are thought not to be able to afford to pay their care costs. For example, a government might undertake to pay the costs of anyone with assets of less than £20,000. People who have slightly more than this (say £30,000) would be expected to pay their way until their resources were lower than this threshold (i.e. they would need to spend £10,000 before the government would start paying).

> An upper threshold or 'cap' so that once people have paid a certain amount of money towards their care costs they are not asked to pay more and care is paid for exclusively by the government.

The UK is currently looking to introduce a cap to the amount a person pays towards the care element of care costs. This will start in 2016. The lower threshold for receiving help is £27,000 in wealth, not including a house if a spouse/partner or dependent lives there, or, if a property would otherwise be empty, the lower threshold is £118,000. If a person has greater income and assets

than these thresholds they will pay until their wealth drops below the threshold or until the total amount they have paid reaches the cap (upper threshold) which will be £72,000. Living and accommodation costs in residential care will continue to be charged to the individual, as there is no equivalent to the Long-term Care Insurance Scheme[24].

In Jersey, a cost cap system was introduced as part of the reform to the Long-term Care Scheme last year. The lower threshold for receiving help is £419,000; anyone who has wealth over this amount will be expected to pay up to a cost cap of £52,120[25].

Where thresholds are set has a significant impact on which parts of the population are most affected by a cap system.

A system 'capping' care costs could significantly control overall long-term care expenditure by the States. It would also allow people to begin to plan for meeting long-term care costs, whereas, without the cap, the cost is an unknown quantity and difficult to plan for.

However, the introduction of such a system in Guernsey and Alderney would not be without controversy given that currently care and support costs are almost exclusively paid for by the States, irrespective of whether the person lives at home, in extra-care housing or in a care home.

There are also equity arguments: such a system invariably protects wealthier older people who have significantly more than the cap

24
UK Department of Health (2014) "Factsheet 6 – The Care Bill – Reforming what and how people pay for their care and support". [Online]. Accessible at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/268683/Factsheet_6_update__tweak_.pdf [accessed 18th May 2015].

25
States of Jersey (2014) "Long-term care scheme: benefits". [Online]. Available at: http://www.gov.je/Benefits/LongTermCare/Pages/LongTermCareBenefits.aspx [accessed 18th May 2015].

in assets, whilst requiring those with moderate savings or assets to spend until they reach the lower threshold. Nonetheless, if the affordability of the care system really does become an issue, introducing thresholds for care cost contributions is an option that will need to be considered.

Including assets in means testing

Under the current Long-term Care Insurance Scheme, if people do not receive a full pension and cannot afford to pay the co-payment for their care home placement or long-stay hospital fees for the Mignot Continuing Care, Duchess of Kent or Lighthouse Wards, they can receive support from Supplementary Benefit. This assistance is means-tested, i.e. the Social Security Department obtain information regarding the individual's resources in order to determine if they are eligible for support. Under this assessment the 'family home' is not taken into account; so, for example, if someone living in a care home has very little income but owns an empty house worth £500,000 they will receive support from the government and will not be required to let or sell the property.

Historically, there has been a strong feeling amongst Islanders that houses should be protected as assets and not taken into account where people are asked to contribute towards care costs; indeed, this was arguably the principal driver behind the introduction of the Long-term Care Insurance Scheme.

However, the last ten years has seen some changes in the Islands. More Islanders now rent and feel unable to purchase a house, and many of these people may be less sympathetic to being asked to

contribute to protect the property assets of others. It is also worth noting that some of those moving into a care home at present already sell their properties (and either invest the funds released or, in some cases, use it to pay 'top up fees'). Others let their properties and use the rental income to pay care home 'top up fees'.

As part of this consultation, it is necessary to re-examine whether property assets should be excluded from the consideration of how to fund long-term care services equitably and sustainably. One possibility would be to propose that people moving into a care home or an extra care flat that they cannot afford to purchase[26], should be expected to either sell their previous home (providing their dependents or immediate family are not still living there) or to let it, with its value forming part of any assessment of ability to pay for accommodation and living costs - and potentially for any contribution towards care and support costs. It is not clear yet whether this will be pursued or what form the inclusion of houses in assessments would take if it were implemented. However, important points of consideration include:

> Managing the risk that people will give away their property to avoid having to pay costs. For example, if someone is seeking to claim from the Long-term Care Scheme in Jersey, property assets which have been transferred in ownership in the ten years preceding a claim will be taken into account[27].

> Making sure that any scheme is fair to dependents or spouses who might still live in the property. In the UK, for example, the value of a house is not taken into account if a

26
Currently, as a matter of policy, people who own property and are moving into a GHA extra-care development are required to purchase a partial ownership flat. There are no flats available for outright purchase.

27
For more about the Jersey Scheme see: http://www.gov.je/Benefits/LongTermCare/Pages/LongTermCareAbout.aspx

spouse/partner or dependent has lived in the house as their main or only home since before the individual with care needs was admitted into residential care[28].

These and other factors may require further consideration pending the responses to this consultation.

Availability of affordable care placements

There are currently no controls on who gets care home placements or at what price. Currently, in order to receive funding from the Long-term Care Insurance Scheme a person needs a NAP certificate confirming their level of need and whether that need would be suitably met in a residential or nursing care home. Once they have this certificate, however, they still need to approach care homes to secure a placement as they are not guaranteed a place. If care home beds become in short supply there is no way to prioritise someone for a bed. There is also no way to ensure that if they cannot afford to pay 'top up fees' to contribute to their care costs, they can secure a place in timely fashion if their sole means of financial support is Long-term Care Benefit.

Without introducing measures to regulate or intervene in the operation of the care home market the only way of mitigating this is by trying to ensure that the expansion of the care home sector is not being restricted by, for example, lack of available land or staff. However, if the latter is unsuccessful, then the States has a duty to ensure that the most urgent cases are provided for and that people who need care are not priced out of the market.

28
For more information on the UK system see Age UK (2015) Factsheet 38 "Treatment of property in the means test for permanent care home provision : http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS38_Treatment_of_property_in_the_means-test_for_permanent_care_home_provision_fcs.pdf?dtrk=true

Eligibility and access to care

In Guernsey, there are currently different systems for identifying whether someone is eligible for publicly funded care and support. The kind of assessment they receive will depend on the kind of support people are trying to access; for example, the assessment for eligibility for community services is different to the assessment for Severe Disability Benefit. Usually their case will be considered by staff members against a set of criteria.

The UK has sought to create greater transparency by publishing a single set of eligibility criteria against which decisions about eligibility for care are justified. The intention was to increase the transparency with which decisions about individual cases were made.

If there is public interest, Guernsey could seek to publish outcomes-based eligibility criteria to increase the transparency of decisions.

Summary

To make the funding system sustainable in future years it is likely that people will personally need to contribute more towards their care costs, in order to reduce the overall financial burden that will otherwise be borne by the entire population to fund States' expenditure on increasing numbers of people with long-term care needs. Whilst final decisions about how to achieve this have not yet been made, the following are being considered:

> Increasing the co-payment so that people in residential or nursing care homes, or long-term hospital care, pay more towards their accommodation and living costs.

> Considering introducing a cap up to which people will have to pay their care costs before they become eligible for States financial support, if this is necessary pending analysis of funding projections.

> Assessing housing assets when undertaking means assessments.

iv. Other strategic issues related to funding

The way in which the funding system is constructed will also influence people's quality of life and wellbeing.

Personalisation of funding systems
One of the criticisms of our current funding system, is that it does not always support choice about how, where and from whom care or support are received. Funds from the Long-term Care Insurance Scheme can only be used to pay for residential or nursing care; funds are not available, for example, to pay for an enhanced domiciliary care package to be delivered into someone's home. Whilst HSSD does provide community care services which are mostly free to the service user, in the private sector there is no option for people to be able to organise or choose their own care and to receive financial support for this. Empowering people to be able to make choices about their care may, therefore, mean adapting the funding system for care and support.

In the UK and in many other countries people with care or support needs are given more choice via 'personal budgets'. A personal

budget is an amount of money set aside by the government to meet someone's care and support needs. The amount of money they receive depends on the level of their need. People then have some choice about how to spend this money. There are a number of ways in which this can be done but these include:

> *Managed personal budgets* – where a social worker works with the person with care needs to identify what services they want to spend their personal budget on from a 'menu' of approved providers, and then arranges for these services to be paid for from the personal budget without the individual needing to contact care agencies themselves or handle the money.

> *Direct payments* – where a cash sum is given to a person with care or support needs to arrange their own care and support. This can include using the personal budget to hire carers directly. In this case the individual manages the care that they receive directly with the suppliers, keeps records of how the money is spent and, if employing directly rather than purchasing services, is responsible for complying with employment legislation.

Personal budgets are designed to support people to make choices about how they receive the care and support they require. Some of the challenges to making personal budgets work well in Guernsey would be:

> *Empowerment vs bureaucracy* – personal budgets aim to empower people to make informed choices about what care services they wish to engage. The design of any personal budget system needs to balance the government's responsibilities to account for how public money has been spent and ensure that care services are safe, with an individual's freedom to engage the support that they want or need. There is a risk that a personal budget system could become overly bureaucratic.

> *Cultural change* – the social workers or other staff who help people to choose how to spend their personal budgets must respect the decisions of the people that they work with. If the approach taken is (unintentionally) paternalistic then staff may prevent people from accessing the services that they want.

> *Creating a market* – in Guernsey at present there are very few private and third sector care providers who cater for people living in their own homes. If the funding system for care changed overnight, people might find that there were no services for them to spend their personal budget on. If personal budgets are developed they might have to be gradually introduced.

> *Specialist services* – there are a lot of people who need general care and support so there is likely to be enough demand to support the development of a competitive market place with several suppliers. However, for those who need very

specialist support this might not be the case, so providing for specialist support may require continued public service provision or careful consideration to ensure that people are not exploited by monopoly providers.

> *Different outcomes for different groups* – in the UK, people with physical disabilities have been found to have better outcomes from holding personal budgets than older people or people with learning disabilities. Research would need to be undertaken into why this has been the case as a prelude to their introduction in Guernsey (if indeed personal budgets are pursued).

> *Legal issues* – if personal budgets are introduced a proper system of regulation will need to be established for home care (domiciliary) providers. If a 'direct payments' system is introduced where people can choose to employ their own carers directly then there will need to be advice and support on people's legal obligations as employers.

It is worth noting that, whilst personal budgets have been pursued in the UK on the belief that they would be more cost effective, existing evidence on cost savings is not yet clear and in many cases it seems that personal budgets have not resulted in significant savings being made[29]. It seems that if personal budgets are pursued in Guernsey, it should not be on the basis that they will save a lot of money, but because other non-financial benefits will accrue and contribute towards the wider objectives of the Strategy in terms of independence and choice.

29
See for example Audit Commission (2010) "Financial management of personal budgets – Challenges and opportunities for councils" p.2. [On-line]. Available at: http://archive.audit-commission.gov.uk/auditcommission/sitecollectiondocuments/AuditCommissionReports/NationalStudies/20101028financialimplicationsofpersonalbudgetssummary.pdf [accessed 8th May 2015].

It is clear that substantial further research should take place if personal budgets are to be considered an option in Guernsey. If considered further, a staged approach to their introduction would likely need to be adopted.

Compensating informal carers
Many people care for and support their family members or friends. In some cases this can be an intensive commitment and some people give up work in order to provide care.

The only financial compensation to carers at present is Carers' Allowance, which provides a small cash benefit (currently £80.08 per week) to carers who care for someone who is severely disabled for more than 35 hours per week.

Whether or not Carers' Allowance should change is closely related to whether personal budgets are adopted in Guernsey. In some countries personal budgets can be used to employ or pay a family member to provide care. How personal budgets relate to carers will need to be carefully considered if they are pursued.

Additional costs associated with living with a disability
Many people with disabilities have higher living costs than an average person since they may have higher transport costs, or may have costs associated with dietary supplements, heating or prescription costs. Severe Disability Benefit, to some extent, offers some compensation for additional costs associated with disability. However, it is also used to purchase care services and therapy. If personal budgets for care services were introduced in Guernsey

thought would need to be given to how Severe Disability Benefit would fit with such a system, and if the purpose of Severe Disability Benefit and Personal Budgets would overlap.

In the UK, where they already have Personal Budgets, there is a 'Personal Independence Payment' which is different from Severe Disability Benefit in two significant ways[30]. Firstly, it is split into two components which are assessed separately – one is intended to be related to additional costs associated with a mobility impairment; the other part is to do with costs for a disabled person associated with Daily Living. This means that someone could claim for one of these elements if, for example, they do not have additional day to day living costs but have significant difficulty getting around they could receive a small amount to contribute towards meeting their mobility needs. Secondly, the Personal Independence Payment has a lower rate payable to people with less severe conditions. Currently the threshold for claiming Severe Disability Benefit is quite high (as the title might suggest) and there is no lower level for people with lower needs.

30 https://www.gov.uk/pip/what-youll-get

Whilst it is not clear whether Severe Disability Benefit would change, the purpose of Severe Disability Benefit here, and the purpose of similar payments in other jurisdictions, needs to be considered and compared if personal budgets are pursued in Guernsey.

Working with the third sector

The community, voluntary and charitable organisations are already actively involved in the community supporting people via day centres, support groups, provision of advice and equipment and so

on. These organisations contribute resources to care and support in the forms of volunteers' time and funds which they raise independently. Whilst it may be possible for some of these organisations to expand the work they do, it is also important that the States supports them adequately and ensures they are effectively targeted and linked in with other service providers. Support may also be needed for organisations to develop the capacity and capability in order that they can do more to support people. The third sector also has the potential to be, and in some cases already is, a significant not-for-profit service provider which the States could commission to provide services on its behalf. It may be that working closely with the third sector can help to provide a wider range of services whilst preventing costs from rising so fast.

TAKE THE SURVEY

You can complete the survey online or download a copy of this document from the States of Guernsey website:

www.gov.gg/slaws

If downloaded, please return responses to:

slaws@gov.gg by email

Or post your response to:

The Supported Living and Ageing Well Strategy
Policy Council
Sir Charles Frossard House
La Charroterie
St Peter Port
GY1 1FH

This consultation process is open for 4 weeks. The final deadline for submission is 22nd July 2015.

If you have any queries or if you would like a printed or large print version please contact us.

Tel: 01481 717134

Email: slaws@gov.gg

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