States of Jersey
States Assembly

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Assemblée des États

Health and Social Security Scrutiny Panel

The Long-Term Care Scheme

Presented to the States on 28th March 2018

S.R.4/2018

CONTENTS

1. Executive Summary

The Long-Term Care Scheme (LTC Scheme) was introduced on 1st July 2014 following States approval of the Long-Term Care (Jersey) Law 2012. The Scheme's main objective is to provide financial support to those who have long-term care needs. The Scheme is designed to ensure that the costs of care are shared fairly across the community and allow individuals and their families to plan for their long-term care. There are three benefits under the Scheme: LTC benefit, LTC support and LTC property loan.

The LTC benefit is available to individuals to meet the costs of their care once they have paid for their own care costs up to a certain level, known as the care cost cap. LTC support is means-tested financial support and is available to individuals to help meet care and living costs in a care home. Financial support is also available to homeowners facing high care bills through a property loan secured against the family home. Whether an individual can access a property loan is dependent on the value and type of assets held by them or their partner.

The Panel agreed to undertake a review of the Scheme in 2017 and predominantly focussed on the efficiency and effectiveness of the Scheme, the assessment process and the overall fairness of the Scheme in operation. The Panel was assisted by two expert advisors - Professor Malcolm Johnson (International Institute on Health and Ageing) and Ms Michelle Galpin and Mr Graydon Bennet (BWCI Consulting Limited).

Professor Johnson believes that the LTC Scheme is amongst the best internationally in terms of the balance of responsibility between the States of Jersey and individuals. He commented that the States of Jersey is to be congratulated on the foresight, political will and expertise that was brought to bear in the creation of the Scheme.

Although in the early stages of implementation there were problems relating to delayed assessments and trained staff shortages, these have now been corrected or are in the process of correction. In terms of the workforce in general however, the Panel has noted that the turnover of social workers has meant that clients and families have been unable to build a relationship with their social worker, which has contributed to a lack of continuity within the service. The Panel believe that there should be a permanent link of one social worker for each client or care home which would ensure that strong working relationships can be formed.

The Panel has found that the LTC Scheme provides for two distinct groups of people, the elderly and those who are born with or develop long-term conditions. For adults claiming the LTC benefit it is important that they are able to access social activities, particularly those that foster social bonds and friendships which support their quality of life. Similarly, older adults are often confined to the house with little stimulation. Professor Johnson explains that these older adults deserve spiritual as well as functional care. Therefore, whatever an individual's care needs are, be it health or social, the Panel considers it important that the Scheme is personalised to the individual.

The Panel has highlighted respite care as a fundamental issue within the Health and Social Care system as a whole. A number of stakeholders and members of the public said respite care was problematic under the Scheme particularly when urgent or unplanned. The Panel believe that a detailed review of respite provision should be undertaken to ensure individuals and their carers are receiving the right respite care. As noted in the Carers Strategy 2017, the need for enough appropriate and high quality respite is considered a significant issue and there is a powerful message from carers that flexibility and personalisation are key to bridging this gap.

In terms of the financial health of the fund, the Panel's advisor, BWCI, explained that the LTC Scheme has only been fully operational in the post-transitional state since January 2016. Therefore, there is limited experience to assess whether the Scheme has reached a stable state in relation to the proportion of claimants in each care level. It is understood that the Minister for Social Security will appoint an actuary to report on both the financial condition of the LTC fund and the adequacy of the contributions being paid in.

BWCI explain that changes of care needs could have implications for the financial stability of the LTC fund. As an example, Professor Johnson made reference to the UK where there has been a marked growth of dementia deaths. People living with dementia often experience "prolonged dwindling" deaths preceded by longer stays in long-term care. Although Jersey statistics do not reflect the same level of dementia deaths, this may be due to a different practice in recording the cause of death on death certificates. BWCI recommend that any anticipated changes in care needs over time, as a result of medical advances in the treatment of diseases and conditions of the elderly, are factored into the model to project the Scheme's financial sustainability.

2. Key Findings

KEY FINDING 1: The Panel's advisor considers that the Long-Term Care Scheme is a good system and is amongst the best internationally in terms of the balance of responsibility between the States of Jersey and individuals.

KEY FINDING 2: 1177 individuals are being supported through the LTC Scheme. Overall there are twice as many women on the Scheme as there are men.

KEY FINDING 3: There is no link between contributions and benefits because only those that pay income tax will contribute to the LTC fund. Some will receive the benefit but not necessarily have contributed to it whilst others will contribute for a long period but will never need to claim from it.

KEY FINDING 4: The LTC Scheme is complex and not easy to understand. A number of submissions made to the Panel complained about this.

KEY FINDING 5: Under the LTC Scheme, individuals are able to apply for a property loan. This has been welcomed by some who feel pleased that this option is available to prevent the necessity to sell their property to pay for care.

KEY FINDING 6: The LTC property loan is a long process and, for claimants residing in a care home, sometimes results in a period of uncertainty for either the individual or the care home.

KEY FINDING 7: Once an assessment of need has been carried out by social workers through a Resource Allocation System, the claim is then processed by the Social Security Department. There are a number of factors that contribute to the application process and there is a 3 week time limitation set on the return of the form in which time clients are required to collect supporting evidence. If there is a breakdown in any of these processes it can result in a delay.

KEY FINDING 8: The flexible care component has been introduced to provide financial support to individuals who have care needs below the level at which they would qualify for the LTC Scheme. Although the flexible care component is part of the Income Support system, the assessment process is undertaken under the LTC mechanism thereby creating a two tier system.

KEY FINDING 9: The LTC Scheme does not cover all care needs. Those who have assessed long-term care needs which fall above the qualifying level for the LTC Scheme are part funded by the Health and Social Services Department. Those who have long-term care needs which fall below the qualifying level for the LTC Scheme are funded by the flexible care component of income support. The different systems create uncertainty over the sustainability of funding streams.

KEY FINDING 10: When the LTC Scheme was first implemented, individuals who applied to join the Scheme experienced delays getting assessed and consequently receiving appropriate care packages. The Panel understands that the system has now improved in terms of waiting times.

KEY FINDING 11: The turnover of social workers has meant that clients (and families) have been unable to build close working relationships with their social workers which has contributed to a lack of continuity within the service.

KEY FINDING 12: A group of carers are receiving respite care which continues to be funded by the Health Department. However, it is possible for people to access the LTC Scheme purely to receive funding for respite, although some carers will need to pay for care whilst respite is provided to them. This differs from the previous arrangements where all respite was provided at no charge to carers.

KEY FINDING 13: The LTC General Information Leaflet offers no explanation on the options for respite care.

KEY FINDING 14: Access to respite care through the LTC Scheme is a fundamental issue. Some people struggle to gain access to respite, particularly when urgent or unplanned. Present arrangements do not meet needs in many cases which risks the provision of care within families.

KEY FINDING 15: Carers make a significant contribution to society by providing unpaid care and support to their loved ones. The pressure on many carers is often high and the impact on their lives is significant, thereby highlighting the importance of sufficient respite provision.

KEY FINDING 16: The implementation of the Regulation of Care Law and the establishment of the Jersey Care Commission are to be welcomed. In hindsight, the Law and its Regulations should have been implemented at the same time as the LTC Scheme, which would have ensured that care providers were regulated to provide appropriate standards of care.

KEY FINDING 17: The LTC Scheme caters for young adults with long-term conditions as well as older aged adults with chronic long-term conditions. At present the Scheme fails to provide sufficient personalised care to the individual. The Scheme must be personalised to the individual so that their health and social care needs are met. A young adult may need their LTC benefit to use for more social related activities compared to an older adult who may need their benefit for more health related care needs.

KEY FINDING 18: Les Amis have raised concerns about the sustainability of their service due to a deflator added for group homes.

KEY FINDING 19: Once an individual has applied for the LTC Scheme, if they are receiving income support, the personal care component is no longer payable. Instead only a small amount for personal expenditure is payable under the LTC Scheme. Therefore individuals no longer have the flexibility to spend the sum of money they receive as the personal care component on living in the community, if their families are the ones providing most of the care.

KEY FINDING 20: The assessment to find out if an individual is eligible to receive the personal care component of income support is undertaken differently and based on different criteria compared to the LTC assessment. Therefore, in some cases it may be more appropriate for an individual to receive the LTC benefit rather than the personal care component of income support.

KEY FINDING 21: There is a risk that vulnerable adults will not receive the care they need because within their families a decision is made not to apply for the LTC benefit, choosing instead to retain a personal care component of income support which they consider essential to provide for the needs of that adult living in the community.

KEY FINDING 22: Although in 2013 the Social Security Minister agreed to report annually on certain key statistical information, this has not happened. Collection and reporting of this information is important in considering assumptions in any future modelling of projected costs.

KEY FINDING 23: The financial demands on the LTC Fund are likely to increase if the next generation of older adults requiring care has fewer assets than the current generation.

KEY FINDING 24: The contribution rate to the LTC Fund will need to increase steadily over the next two decades to ensure that the Fund can sustain the expected increase in benefit expenditure caused by the ageing demographic.

3. Recommendations

Please note: Each recommendation is accompanied by a reference to that part of the report where further explanation and justification may be found.

RECOMMENDATION 1: The Social Security Department should review its explanatory literature and streamline the information provided in the "LTC General Information" leaflet with a view to explaining the Scheme more clearly. This should be undertaken by Q3 2018 [section 5].

RECOMMENDATION 2: The Minister for Social Security should consider whether there are aspects of the LTC Scheme which could be simplified for the benefit of both claimants and administrators. The Social Security Department should review these processes and make the necessary changes and report back to the States by Q3 2018 [section 5].

RECOMMENDATION 3: The Social Security Department should set up an online facility so that information could be filled in by the applicant in order to speed up the application process. This should be established before the end of 2018 [section 5].

RECOMMENDATION 4: Family members should be involved to a greater extent in providing information relevant to a claimant's assessment [section 5].

RECOMMENDATION 5: The Minister for Social Security should ensure that all thresholds, disregards and benefit levels of the LTC Scheme are regularly updated and adjusted consistently. Any proposed inconsistency should be subject to detailed consultation and justified by Ministers [section 5].

RECOMMENDATION 6: The Minister for Social Security should investigate ways of speeding up the process of applying for a LTC property loan [section 6].

RECOMMENDATION 7: The Imosphere Assessment tool should be independently evaluated and the results published before the end of 2018 [section 7].

RECOMMENDATION 8: All claimants should receive annual statements, including details of LTC benefit or support paid and (if applicable) their progress towards the care costs cap [section 7].

RECOMMENDATION 9: The Health and Social Services Department should ensure that there is a dedicated social worker for each client on the LTC Scheme. This would ensure a continuity of care across the board and ensure that strong working relationships can be formed with each client. This should be implemented by Q4 2018 [section 7].

RECOMMENDATION 10: Where care is being provided in a care home, the Health and Social Services Department should ensure that there is a permanent link of one social worker to ensure continuity. This should be implemented by Q4 2018 [section 7].

RECOMMENDATION 11: The Social Security Department and Health and Social Services Department should make it better known that people can access the LTC Scheme purely to receive an allowance to use for respite care. This should be undertaken in various ways but should include a full explanation on the options for respite care within the LTC General Information Leaflet, or by producing a standalone leaflet on respite care by Q3 2018 [section 8].

RECOMMENDATION 12: Both the Minister for Health and Social Services and Minister for Social Security should carry out a detailed review of respite provision and its funding. The review should include all aspects of Priority 1 within the Carers Strategy 2017 ("Getting the right Respite"). The outcomes of the review should be reported back to the States before the end of 2018 [section 8].

RECOMMENDATION 13: Since the introduction of the LTC Scheme a new market in care provision has been created. The Social Security Department should monitor the charges made by care homes and report to the States on an annual basis [section 9].

RECOMENDATION 14: The Social Security Department and Health and Social Care Department should consult with adults with long-term conditions, their carers and the Voluntary and Community Sector which supports them. The purpose would be to better assess the needs of young adults and the ways of meeting those needs. The Department should report back to the States with its findings before the end of 2018 [section 9].

RECOMENDATION 15: The Social Security Department should monitor the situation with Les Amis in terms of the deflator added for group homes and engage with the organisation recognising the importance of the service they provide [section 9[.

RECOMMENDATION 16: In pursuing a policy presumption that it is preferable to provide care in people's own homes, the Minister for Health and Social Services should ensure there is awareness of the risks of depression and isolation amongst older people. Ways to counteract this should be included within policy [section 9].

RECOMMENDATION 17: Statistical information about the proportion of claimants in each care level and the transitions between levels should be monitored and published as part of the Social Security Minister's annual report [section 10].

RECOMENDATION 18: The Social Security Department should ensure that information about the assets of those entering care is recorded, so that any trends in the amount of these assets can be monitored. This information could be of assistance in any future modelling of the LTC Scheme. The appropriate processes should be put in place by Q3 2018 [section 10].

RECOMMENDATION 19: Any anticipated changes in care needs over time, as result of medical advances, should be factored into the model to project the LTC Scheme's financial sustainability [section 10].

RECOMMENDATION 20: The Panel's advisor notes that in the UK there has been a marked growth of dementia deaths. The incidence of dementia in Jersey and the recording of causes of death should be researched further in the interests of statistical accuracy and future modelling. The outcome should be reported to the Panel by Q3 2018 [section 10].

RECOMMENDATION 21: As recommended by the Panel's advisor, BWCI, the actuarial review of the LTC Fund being conducted in 2018 should include an analysis of actual experience to date. The Social Security Department should use this as the starting point for determining realistic assumptions for the future financial modelling of the LTC Scheme [section 10].

RECOMMENDATION 22: The practice of progressively reducing the amount of LTC benefit or support paid whilst a claimant is in hospital should be reviewed as it seems unfair that the claimant should have to make up any balance owed to his/her care home for the period spent in hospital [section 11].

RECOMMENDATION 23: The LTC Scheme should cover short term costs incurred when a period of more intensive care is needed for a claimant living at home. This can arise if a final period of palliative care is needed to allow a patient to pass away in his or her own home [section 11].

RECOMMENDATION 24: The LTC Scheme should acknowledge that many claimants spend considerable amounts adapting their accommodation to meet their care needs e.g. fitting stair lifts, installing accessible washing facilities, purchasing adjustable beds. It is suggested that such capital expenditure should be regarded as part of relevant expenditure to reach the care costs cap [section 11].

RECOMMENDATION 25: The LTC Scheme should also acknowledge that claimants receiving live-in care in their own homes have additional expense in providing food, heat, power, transport and so on for their carer. It is suggested that an allowance should be made so that these expenses are regarded as part of relevant expenditure to reach the care costs cap [section 11].

4. Introduction

Following States approval of the Long-Term Care Law in 2011, the Social Security Department created a Long-Term Care Scheme in 2013. The Scheme's main objective is to provide financial support to individuals who have long-term care needs and who are being cared for either in their own home or in a care home. The Long-Term Care Scheme ("LTC Scheme") was first introduced in 2014.

The Panel's review has predominantly focused on the efficiency and effectiveness of the LTC Scheme, the assessment process and the overall fairness of the Scheme in operation. In addition, the Panel has also scrutinised the financial aspects of the Scheme, both as it exists now in only its third year of operation and how costs might change over the medium and longer term. The Panel's Terms of Reference for the review can be found in appendix three.

The Panel appointed Ms Michelle Galpin and Mr Graydon Bennet from BWCI Consulting Limited to assist with the financial aspects of the LTC Scheme. The Panel also engaged Professor Malcolm Johnson from the International Institute on Health and Ageing to assist with general matters of the Scheme and to help identify key issues from the evidence received. Both of the advisors' reports are appended to this report and are referenced throughout[1].

The Panel asked for views on the LTC Scheme during March and April 2017 and received around 50 submissions from members of the public and the voluntary and community sector. In addition, the Panel held several Public Hearings with various agencies and Ministers during July and September 2017. The Panel is sincerely grateful to those who contributed to its review.

[1] Please note that the advisor reports reflect the LTC rates in 2017. The LTC rates have since been revised in 2018 as reflected in the Ministerial Order

5. The Long-Term Care Scheme: Overview

The LTC Scheme was introduced on 1st July 2014 and is a ring-fenced fund held within the Social Security Department. In 2015, both the Social Security Department and the Health Department worked together to deliver the benefit in its first full year of operation[2].

The purpose of the LTC Scheme is to support the growing care costs of the ageing population as well as providing means tested payments and loans to people who would otherwise struggle with the cost of care. It became clear during the review that the Scheme provides for two distinct groups of people - the elderly and those who are born with or develop long-term conditions.

The LTC Scheme also provides a non means-tested benefit which removes the worry of high costs often associated with long-term care,[3] for example if someone was involved in a road accident which resulted in long-term care needs.

The Scheme is financed by taxpayer contributions into a ring-fenced fund: these started at 0.5% of taxable income on 1st January 2015 and increased to 1% on 1st January 2016. Initial funding was provided by the States to allow benefits to be paid from 1st July 2014, whilst collection of the contributions from taxpayers started in 2015[4].

The contribution rate is set to increase in the future as costs increase[5]. Modelling work commissioned by the Social Security Department at the time predicted that care costs are set to more than double by 2044[6] due to the ageing population. In that regard, the contribution rate is set to rise over the next 30 years to just under an estimated 3% by 2044[7].

The ageing population has been on the political agenda in recent years where the over 85s are the fastest growing sector. The Panel's advisor, Professor Malcolm Johnson, believes that the LTC Scheme is amongst the best internationally in terms of the balance of responsibility between the States of Jersey and individuals[8]. "*What does need to be said is that the Jersey Scheme was fashioned with the benefit of international thinking and practice. On the one hand it is more comprehensive and integrative than the Guernsey Scheme; bolder and more financially generous than successive UK governments have been willing to introduce. Moreover the projections of fiscal sustainability appear to be sound*".[9]

[2] R.104/2016 "Minister's Report" Social Security Department, published 11th October 2016, p.13
[3] R.104/2016 "Minister's Report" Social Security Department, published 11th October 2016, p.13
[4] R.104/2016 "Minister's Report" Social Security Department, published 11th October 2016, p.44
[5] R.104/2016 "Minister's Report" Social Security Department, published 11th October 2016, p.13
[6] P.99/2013 "Long-Term Care Scheme" lodged 22nd August 2013, p.3
[7] P.99/2013 "Long-Term Care Scheme" lodged 22nd August 2013, p.3
[8] Briefing paper, Professor Malcolm Johnson, 15th August 2017
[9] Professor Johnson report, appendix 1

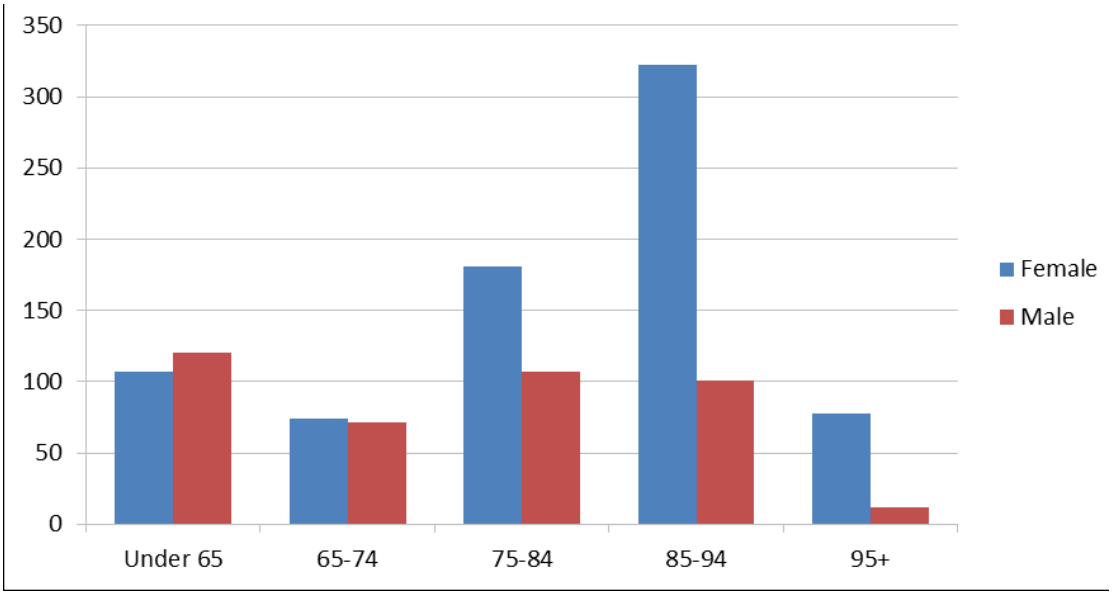
KEY FINDING 1: The Panel's advisor considers that the Long-Term Care Scheme is a good system and is amongst the best internationally in terms of the balance of responsibility between the States of Jersey and individuals.

How many people are receiving the Long-Term Care Benefit?

As of February 2018, 1177 individuals were being supported through the LTC Scheme. The table below was received from the Social Security Department and groups the data by age:

Age Ranges	LTC Recipients
18 - 19	6
20 - 29	39
30 - 39	25
40 - 49	32
50 - 59	86
60 - 69	87
70 - 79	212
80 - 89	419
90 - 99	260
100 - 109	11
Total	**1177**

The graph below illustrates the demographic profile of those registered onto the Scheme, and shows that overall there are almost twice as many women on the Scheme as there are men, and that this proportion grows with older age[10]:



KEY FINDING 2: 1177 individuals are being supported through the LTC Scheme. Overall there are twice as many women on the Scheme as there are men.

[10] R.92/2017 "Minister's Report 2016" Social Security Department, published 24th July 2017, p.36

Who is eligible to receive the Long-Term Care benefit?

To qualify for the LTC Scheme, an individual must satisfy the following conditions[11]:

- Resident in Jersey for 10 years immediately before applying or be resident for 10 years as an adult in the past and for another year immediately before applying;
- Aged 18 or over;
- Care must be provided at an approved care home or through an approved care package at home;
- The individual's care needs must have been assessed as being above a minimum level.

The 10 year residency requirement

The residency condition ensures that the provisions for the LTC Scheme do not incentivise those needing long-term care to move to or return to Jersey purely to receive care. The Regulations setting out the residency conditions (P.136/2013) note that the conditions would "*ensure that individuals are likely to have made a reasonable contribution to the LTC fund – and potentially in other ways to the wellbeing of the Island community"*[12]. However, the Panel notes that there is no link between contributions and benefits because only those that pay income tax will contribute to the fund. Those with incomes below the income tax threshold do not contribute to the LTC fund. Older adults in particular may have incomes that fall below this threshold and therefore some will receive the benefit but not necessarily have contributed to it[13]. It is noted however that most people with long-term conditions do not have significant income and will also be below the tax threshold.

Conversely, there will also be a proportion of individuals who will contribute towards the Scheme for a long period but will never need to use it.

KEY FINDING 3: There is no link between contributions and benefits because only those that pay income tax will contribute to the LTC fund. Some will receive the benefit but not necessarily have contributed to it whilst others will contribute for a long period but will never need to claim from it.

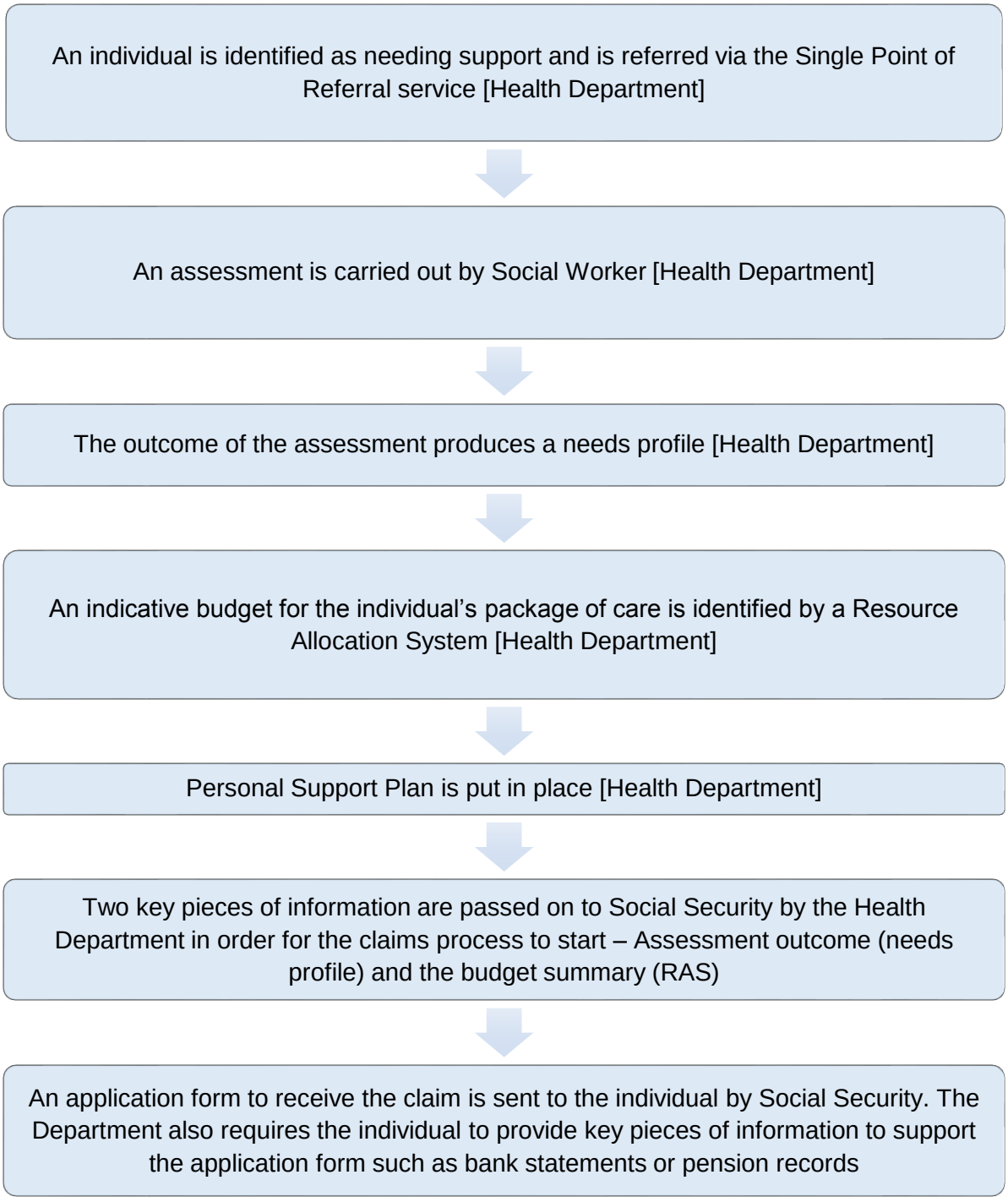
Long-Term Care Referral Process

The LTC Scheme is administered by both the Health Department and Social Security Department. In simple terms, the Health Department deals with the needs of the individual and identifies an indicative budget based on those needs. The Social Security Department then administers the claim. There are lots of elements to this process including assessments, application forms and official personal documentation required from the individual.

Individuals are able to refer themselves to the Scheme through the Single Point of Referral (S.P.O.R) service within the Health Department. S.P.O.R is an open referral system so as well as individuals referring themselves, the referral can come from anybody such as family, neighbours

[11] Long-Term Care Scheme, P.99/2013, lodged on 22nd August 2013, p.4
[12] P.136/2013 "Draft Long-Term Care (Residency Conditions) (Jersey) Regulations 201-"p.3
[13] P.136/2013 through to P.142/2013 Comments, presented to the States on 3rd December 2013 by the Health, Social Security and Housing Scrutiny Panel, p.9

or GPs[14]. The Panel explains this process in further detail throughout the report but at high level can be summarised as follows:



Complexity of the Scheme

The LTC Scheme is a complex system and is not easy to understand. The Social Security Department has provided a "LTC General Information" leaflet which is publically available and explains the different aspects of the Scheme. A number of submissions made to the Panel were about its complexity and how difficult it is to understand:

[14] Briefing on the Long-Term Care Scheme, 31st March 2017

Submission 2.43
"My mother, during her illness, would probably not have queried anything & I suspect an elderly person dealing with these applications on behalf of a spouse may find the whole process overwhelming.

I have found the whole process extremely frustrating & somewhat confusing".

Submission 2.20
"I had to call upon the ltcs team for advice and clarification, they were a great help and I appreciated their support. They also found it confusing and hard to understand".

Jersey Alzheimer's Association
"Of necessity this scheme is complex, making it harder for most people to understand and then communicate to others.

The documentation related to the LTC scheme is very complex and assumes a high level of comprehension from its readers. (Lawyers, accountants and doctors have asked me for help because they find it so difficult to understand.) I think that a simplified version of the documentation would be very beneficial to supplement this".

KEY FINDING 4: The LTC Scheme is complex and not easy to understand. A number of submissions made to the Panel complained about this.

RECOMMENDATION 1: The Social Security Department should review its explanatory literature and streamline the information provided in the "LTC General Information" leaflet with a view to explaining the Scheme more clearly. This should be undertaken by Q3 2018.

The Panel's advisor, BWCI, also identified that the structural complexity of the LTC Scheme, particularly the interaction of the benefit payments, support payments, care cost cap and asset disregard level limits, is not easy to understand[15]:

"In our view the degree of complexity is of some concern, particularly if claimants do not have the assistance of financially literate family members or friends to support them when:

1. *Making the decision to apply for financial assistance under the LTCS*
2. *Completing the application process and financial disclosures required to access the LTCS, and*
3. *Undergoing the assessment process to determine the level of their care needs"*[16].

BWCI recommended that consideration should be given as to whether there are aspects of the LTC Scheme which could be simplified for the benefit of both claimants and administrators. The Chairman of the Primary Care Body suggested that the process could be streamlined by having an online facility. This facility could enable people to fill in information about themselves and what they might need in terms of care. This would ensure that all the information would be easily accessible during any subsequent meeting with a social worker, which could speed up the process[17].

[15] BWCI Report, appendix 2
[16] BWCI Report, appendix 2
[17] Submission 2.1, Dr Nigel Minihane, 20th March 2017

The Panel also heard of some instances where communication between the Social Security Department and applicants had, at times, been lacking:

> **Submission 16**
> *"The staff who are administering the scheme appear to be lacking in simple administrative skills. They do not return telephone calls and neither do they acknowledge written communications. Keeping applicants in the loop with information is so important, particularly when they are elderly and worried".*

> **Submission 2.43**
> *"The paperwork had an incorrect date of admission to Beaumont Villa as late October 2016. I immediately emailed the same officer at Social Security providing a breakdown of the dates my father was cared for…. A month later, I still had not received a response….. I emailed Social Security about the lack or reply & was told they were waiting to hear from the health department".*

> **Submission 2.49**
> *"It is difficult to speak to/communicate with the long-term care team and get a response or relevant guidance".*

During a Public Hearing with the Minister, the Department recognised that the information on the Scheme can be complicated and it was looking at ways in which communication could be improved:

> **Policy Director:**
> *"As the Minister said, it is a scheme that is very flexible in different ways. Giving people all the information, I mean we have been accused of providing very complicated information and too much information. That is because our current leaflet tells you all the things that are available. It does not tell you what you need. So we need to move to a system which can be more personalised in the information we give people at an early stage, it would be great. That is quite a sophisticated task to do. So we are thinking about that and we are working very hard on our communications, on having some online tool that you can answer some very simple questions and that you can go in and get some information about what you might be entitled to*"[18].

RECOMMENDATION 2: The Minister for Social Security should consider whether there are aspects of the LTC Scheme which could be simplified for the benefit of both claimants and administrators. The Social Security Department should review these processes and make the necessary changes and report back to the States by Q3 2018.

RECOMMENDATION 3: The Social Security Department should set up an online facility so that information could be filled in by the applicant in order to speed up the application process. This should be established before the end of 2018.

RECOMMENDATION 4: Family members should be involved to a greater extent in providing information relevant to a claimant's assessment.

RECOMMENDATION 5: The Minister for Social Security should ensure that all thresholds, disregards and benefit levels of the LTC Scheme are regularly updated and adjusted consistently. Any proposed inconsistency should be subject to detailed consultation and justified by Ministers.

[18] Public Hearing with the Minister for Social Security, 18th September 2017, p.10

6. What is provided under the Long-Term Care Scheme?

The LTC Scheme is designed to ensure that the costs of care are shared fairly across the community and allow individuals and their families to plan for their long-term care. There are three benefits under the Scheme:

1. LTC benefit
2. LTC support
3. LTC Property Loan

Long-Term Care Benefit

The LTC benefit is available to individuals to meet the costs of their care once they have paid for their own care costs up to a certain level. This is known as the "care costs cap" and in 2018 is set at £55,300 for a single person, or £82,950 for a couple. The benefit is paid at 4 levels depending on the type and level of care needed. The weekly maximum rates from 2018 were set at[19]:

Level of standard care	Weekly standard care cost/LTC Benefit	Number of weeks to reach care cost cap
1 (lowest)	£374.78	148
2	£571.97	97
3	£826.77	67
4 (Highest)	£1039.50	53

Long-Term Care Support

Long-term care support is means-tested financial support and is available to individuals to help meet care costs and living costs in a care home (depending on the income and assets of the household in which the individual lives).

Long-term care support is available to individuals whose income is not enough to meet these costs and whose total assets are below £419,000. People receiving care at home can also claim long-term care support to help cover the costs of their care and if necessary can claim this alongside an income support claim[20].

Standard Co-Payment

If an individual receives care in a care home, the care home fee will be made up of the standard care cost for their care level plus a co-payment that covers the costs of living in a care home (i.e. food and accommodation). Under the LTC Scheme there is a single standard co-payment rate for everyone that lives in a care home (£332 per week however the co-payment will depend on the choice of home and any extra services or facilities received as some homes charge more than others)[21].

The co-payment does not count towards the care cost cap (£55,300) and will remain the individual's responsibility even after the care costs cap has been reached. Financial assistance

[19] https://www.jerseylaw.je/laws/enacted/Pages/RO-132-2017.aspx
[20] R.104/2016 "Minister's Report 2015" Social Security Department, published 11th October 2016, p.44
[21] Long-Term Care Scheme Leaflet - p.9

may be available from Social Security to help meet the standard co-payment, depending on the income and assets of the individual and their partner[22].

If care is received in the home, individuals do not need to make a co-payment because they will meet their own living costs. If individuals need assistance with living costs, support may be provided through income support[23].

If a couple both receive long-term care at some time (even years apart) each will have a care costs record (as would a single individual). If neither partner has reached the individual total of £55,300 but the total value of care costs for both partners reaches £82,950 this will meet the care costs cap and both will be eligible to receive the LTC benefit that covers the standard care costs for the rest of their time in care. If one partner reaches the single £55,300 care costs cap and starts to receive the LTC benefit, then the other partner will need to accumulate the difference between this figure and the combined cap (i.e. £27,650) to qualify to receive the LTC benefit[24].

Long-Term Care Property Loans

One of the objectives of the LTC Scheme is to safeguard against someone having to sell their family home in order to pay for their care. Therefore, financial support is available to homeowners facing high care bills through a property loan secured against the family home. Loans are interest bearing at a rate of 0.5% above the Bank of England base rate[25]. In most cases the loan has to be repaid when the property next changes hands, however if a partner or unpaid carer remains living in the property after an individual has died, the loan is only due to be repaid once that person either dies or stops living in the home.

Whether an individual can access a property loan is dependent on the value and type of assets held by them or their partner. For example:

- If the value of the family home is more than £394,000 and the value of other assets (including a partner's) is less than £25,000 then the LTC Scheme may be able to offer support towards the cost of an individual's care package through a property loan.

- If the value of all assets (including a partner's) is less than £419,000 and an individual's care package costs more than standard rates, then the LTC Scheme may be able to offer support through a property loan to cover additional costs.

- If the value of the family home is more than £394,000 and the value of other assets (excluding the family home) is greater than £25,000 then a property loan would not be available to the individual.

The table below sets out the rules for LTC support and property loans[26]:

[22] Long-Term Care Scheme Leaflet - p.9
[23] Long-Term Care Scheme Leaflet - p.9
[24] Long-Term Care Scheme Leaflet - p.12
[25] R.92/2017 "Minister's Report 2016" Social Security Department, published 24th July 2017, p.36
[26] Long-Term Care Scheme Leaflet - p.15

Total value of all assets	Below £419,000	Below £419,000	Above £419,000	Above £419,000	Above £419,000
Value of family home	Not a home owner	Below £419,000	Below £394,000	Above £394,000	Above £394,000
Value of all other assets	Below £419,000	Below £419,000	Above £25,000	Below £25,000	Above £25,000
Am I likely to receive LTC support?	**Yes**	**Yes**	**No**	**No**	**No**
Am I likely to need to use some of my other assets?	**No**	**No**	**Yes**	**No**	**Yes**
Am I likely to be offered an LTC property loan?	**Not a home owner**	**Yes, if you have additional costs**	**Yes, if you have additional costs**	**Yes**	**Not immediately**
Will I be eligible for the LTC benefit when I reach the care costs cap?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**

If an individual has a property that is below the asset disregard level, and is not living in it, the Social Security Department expects that an income would be generated and that income would go towards the cost of their care (i.e. reducing the need for means-tested benefits). However, no income is required from a family home if it is still occupied by the claimant, their partner, unpaid carer or any dependent children[27].

The Panel hopes the following scenarios will provide context in relation to the information provided above[28].

Scenario 1 - Couple pensioner who have a property worth £391,000 savings of £25,000 (total assets £416,000) and a full States pension as their only income.

Care at home:

If one of the couple was eligible for the LTC benefit and received care at home, they would not need to use their assets to pay toward their care costs. A full married States pension is worth £349

[27] Information received from the Social Security Department, August 2017
[28] The scenarios were provided by the Social Security Department

per week. As this is less than the LTC allowance provided for a couple living at home they would not need to use any of their income towards their standard care costs. They would receive means-tested assistance and the fund would pay for their standard care costs from day 1. As the couple is living at home, they are not liable for the co-payment of £332 per week (or the personal allowance of £36 per week) so they would be able to use their full States pension to cover their living expenses.

Care home: The pensioner with care needs has moved into a care home and their partner remains at home.

If this pensioner was eligible for the LTC benefit and received care in a care home, they would not need to use their assets to pay towards their care costs. The partner remaining at home is allocated a single allowance plus an allowance for the upkeep of the property. The partner in the care home is allocated £36 per week for their personal allowance. If there is any income remaining after these allowances have been deducted from the pension, this will be used towards their standard care costs and the co-payment. As the net income does not cover the standard care costs and the standard co-payment in this example they would receive means-tested support for the remaining costs (paid from the fund). The pensioner can also choose to take a property bond to meet any top up costs in the care home. Once the care cap is reached, the LTC benefit will meet the standard care costs. As the net income in this example will be low, the pensioner will probably continue to receive means tested support for the standard co-payment but will need to meet any top up costs from the bond. The couple can draw on the £25,000 of savings at any time without any impact on the LTC claim.

Scenario 2 - Couple pensioner who have a property worth £500,000, savings of £25,000 (total assets £525,000), and a full States pension as their only income.

Care at home:

If one of the couple was eligible for the LTC benefit and received care at home, they would need to use some of their assets to meet the £55,300 cap. A full married States pension is worth £349 per week. As this is less than the LTC allowance provided for a couple living at home they would not need to use any of their income towards their standard care costs. They will not be expected to use their savings of £25,000 but will be offered a property bond against the £500,000 property. As the couple are living at home, they are not liable for the co-payment (or personal allowance) so they would be able to use their full States pension to cover their living expenses.

Care home: The pensioner has moved into a care home and their partner remains at home.

If this pensioner was eligible for the LTC benefit and received care in a care home, they would need to use some of the value of their property to pay towards their care costs.

The partner remaining at home is allocated a single allowance plus an allowance for the upkeep of the property. The partner in the care home is allocated £36 per week for their personal allowance. If there is any income remaining after these allowances have been deducted from the pension, this will be used towards their standard care costs and the co-payment. As the net income does not cover the standard care costs and the standard co-payment in this example they would be offered a property bond to cover the remaining costs and any top up costs in the care home. Once the care cap is reached, the LTC benefit will meet the standard care costs. As the net income in this example will be low, the couple will probably continue to use the bond to meet the balance of the co-payment and any top up costs from the bond.

The couple can draw on the £25,000 of savings at any time without any impact on the LTC claim.

Scenario 3 - Single pensioner who has a property worth £391,000 savings of £25,000 (total assets £416,000) and a full States pension as their only income.

Care at home:

If this single pensioner was eligible for the LTC benefit and received care at home, they would not need to use their assets to pay toward their care costs. A full States pension is worth £209 per week. As this is less than the LTC allowance provided for a single person living at home they would not need to use any of their income towards their standard care costs. They would receive means-tested assistance and the fund would pay for their standard care costs from day 1. As the person is living at home, they are not liable for the co-payment of £332 per week (or the personal allowance of £36 per week) so they would be able to use their full States pension to cover their living expenses.

Care home: The pensioner has moved into a care home and has rented their empty property out for £250 per week.

If this single pensioner was eligible for the LTC benefit and received care in a care home, they would not need to use their assets to pay towards their care costs. The income received from the rent is added to their pension with allowances made for the costs of maintaining the property and they retain £36 per week for their personal allowance. They will need to use the net income towards their standard care costs and the co-payment. As the net income does not cover the standard care costs and the standard co-payment in this example they would receive means-tested support for the remaining costs (paid from the fund). The pensioner can also choose to take a property bond to meet any top up costs in the care home. Once the care cap is reached, the LTC benefit will meet the standard care costs and pensioner will only need to meet the standard co-payment and any top up costs from their own income and the bond, if necessary. The pensioner can draw on the £25,000 of savings at any time without any impact on the LTC claim.

Scenario 4 - Single pensioner who has a property worth £500,000, savings of £25,000 (total assets £525,000), and a full States pension as their only income.

Care at home:

If this single pensioner was eligible for the LTC benefit and received care at home, they would have enough assets to meet the £55,300 cap. However, they will not be expected to use their savings of £25,000 but will be offered a property bond against the £500,000 property. As the person is living at home, they are not liable for the co-payment (or personal allowance) so they would be able to use their full States pension to cover their living expenses.

Care home: The pensioner has moved into a care home and has rented their empty property out for £350 per week.

If this single pensioner was eligible for the LTC benefit and received care in a care home, they would need to use some of the value of their property to pay towards their standard care costs until the care cap is reached. The income received from the rent is added to their pension with allowances made for the costs of maintaining the property and they retain £36 per week for their personal allowance. They will need to use the net income towards their standard care costs and the co-payment. In this example, the net income does not cover the standard care costs and the standard co-payment and they will be offered a property bond to meet these remaining standard costs as well as any top up costs they may have.

Once the care cap is reached, the LTC benefit will meet the standard care costs and pensioner will only need to meet the standard co-payment and any top up costs from their own income and the bond, if necessary. The pensioner can draw on the £25,000 of savings at any time without any impact on the LTC claim.

According to the submissions received from members of the public, property loans do not appear to be a contentious area of the Scheme. In a submission received from the Jersey Alzheimer's Association they said: *"…people have been pleased that this option is available to help protect their property and the need to sell it to pay for care*"[29].

It appears that the main contention with property loans is that it can be a long process which results in a period of uncertainty for either the individual or the care home. The Community Visitor for St Helier Care Homes explained:

> **Deputy J.A. Hilton:**
> *"Have you ever been involved with anybody who has had a property bond on their property to pay the long-term care fund?"*
>
> **Community Visitor, Parish of St. Helier:**
> *"Yes."*
>
> **Deputy J.A. Hilton:**
> *"You have. Did the client concerned, were they fully conversant with what was going on and did they understand it? How did the whole process operate, as far as you were concerned?"*
>
> **Community Visitor, Parish of St. Helier:**
> *"Well, luckily there were family involved in this one and it was the family that were making the application on behalf of their mother. But it is a scenario that I have where I have a large outstanding debt because it has taken a long time for it to be ... so it has taken since January for this one. We have had no money since January for them because the family are waiting for the terms of the property bond, which only went out I think last week to them. So they have yet to accept the terms of the property bond before they start receiving some funding."*
>
> **Deputy G.P. Southern:**
> *"So that is a problem not necessarily for them but for you to then give it?"*
>
> **Director of Finance, Parish of St. Helier:**
> *"I think if you are on ... just to put a bit of perspective, when you are on care level 1 the average level of debt is about £3,000 per month so any delays it racks it up fairly quickly. Also I think the stress level as well goes on to the resident because they think: "Do I have to pay this money?" Twelve weeks does not sound like a lot but it works out effectively £12,000, it is a lot of money."*[30]

The Social Security Department commented that registering a charge against a property is a significant step and the Department must ensure that the claimant is eligible for a loan and that they have had the opportunity to take independent financial advice before signing the application. Furthermore the Department commented that although these steps take time to complete, this process has now been specifically provided for in legislation and represents a significant improvement on the previous legal position.

KEY FINDING 5: Under the LTC Scheme, individuals are able to apply for a property loan. This has been welcomed by some who feel pleased that this option is available to prevent the necessity to sell their property to pay for care.

[29] Written Submission by Jersey Alzheimer's, received 13th April 2017
[30] Public Hearing with Community Visitor of Care Homes, 25th July 2017, p.28/29

KEY FINDING 6: The LTC property loan is a long process and, for claimants residing in a care home, sometimes results in a period of uncertainty for either the individual or the care home.

RECOMMENDATION 6: The Minister for Social Security should investigate ways of speeding up the process of applying for a LTC property loan.

7. The Assessment Process

The Resource Allocation System

The Health Department uses a Resource Allocation System (RAS) to support decision making in the setting of personal budgets with eligible social care needs. The RAS is used to provide an estimated budget as a guide to what money may be made available through the LTC Scheme to meet an individual's assessed needs[31].

How does it work?

- The RAS software takes scores of information collected by the social worker about the individual's needs and circumstance during the assessment process and feeds these into a formula.[32]

- The formula then uses an algorithm (calculation) owned by an assessment tool called Imosphere (formally FACE). This is weighted to allow for local differences in the costs of care and support, to provide an indicative budget of the amount of money likely to be required to meet the individual's needs. [33]

The Panel's Advisor, Professor Johnson, explains that well founded and skilled assessment processes which lead to carefully crafted personal care plans, are central to the success of the LTC Scheme. In terms of the Imosphere system, Professor Johnson felt that there were further questions to be asked about the validation of the tools:

> **Professor Malcolm Johnson**
> *"Repeated internet searched to find copies of FACE [Imosphere] Assessment tools failed to yield information - perhaps because of commercial copyright protection. But more disturbing, I could find no independent evaluations of the FACE tools. All the recognised assessment tools widely used in hospitals and care homes have been extensively tested and reported in peer-reviewed journals. To be able to find no such evaluation articles is concerning*[34]."

RECOMMENDATION 7: The Imosphere Assessment tool should be independently evaluated and the results published before the end of 2018.

Claim Process

Once an assessment of need has been carried out by social workers via the Resource Allocation System, the claim is then processed by the Social Security Department. There are a number of factors that contribute to the application process. The Panel was told in a Public Hearing with the Community Visitor of St Helier Care homes that the application form to apply for funding is a 12 page document which requires completion by the client, relative, friend or advocate and can only be sent out by Social Security when the care needs of the applicant have been assessed[35]. There

[31] Report to Cabinet Member for Adult and Community Services, 6th January 2016, Lancashire County Council
[32] Report to Cabinet Member for Adult and Community Services, 6th January 2016, Lancashire County Council
[33] Report to Cabinet Member for Adult and Community Services, 6th January 2016, Lancashire County Council
[34] Professor Johnson report, Appendix one
[35] Public Hearing with the Community Visitor of St Helier Care homes, 25th July 2017, p.4

is a 3 week time limitation set on the return of the form in which time clients are required to collect supporting evidence such as bank statements, pension confirmations and other official documents[36].

> **Community Visitor of St Helier Care Homes:**
> *"….there are a number of factors contributing to the application process, not all under the remit of LTC, and a breakdown in any of these processes will result in a delay"*[37].

KEY FINDING 7: Once an assessment of need has been carried out by social workers through a Resource Allocation System, the claim is then processed by the Social Security Department. There are a number of factors that contribute to the application process and there is a 3 week time limitation set on the return of the form in which time clients are required to collect supporting evidence. If there is a breakdown in any of these processes it can result in a delay.

RECOMMENDATION 8: All claimants should receive annual statements, including details of LTC benefit or support paid and (if applicable) their progress towards the care costs cap.

Low and high level care needs (policies 1 and 2)

Two approaches are used when individuals who have assessed long-term care needs fall above or below the qualifying level for the LTC Scheme. The Panel has heard them being referred to as policies 1 and 2. Their formal titles are the "flexible care component" (policy 1) and the "HSSD policy on funding adults assessed as having complex long-term care needs" (policy 2).

On this issue Professor Johnson said: "*Making such a refinement in response to the situations of beneficiaries demonstrates sensitivity and willingness to make adjustments. Yet there is a downside to the addition of further complexity and increases in the number of thresholds. As the established profile of needs becomes clearer there may be benefit in recalibrating in order to return to four categories*.[38]"

<u>The Flexible Care Component</u>

Income support currently includes three levels of the personal care component provided at fixed weekly amounts (the highest level of personal care component is set at just below £150 per week). Since the LTC Scheme was implemented it has been providing financial support for individuals with high level long-term care needs. The lowest level of care included within the LTC Scheme is just over £350 per week.

Individuals with care costs in the range of £150 to £350 per week are not covered by either the LTC Scheme or the income support system. Individuals with care needs that do not meet the minimum level set out in the LTC Law may still need a regular care package. If the cost of this package exceeded £150 a week this was not previously catered for under the income support scheme. In order to provide financial support to these individuals a flexible care component was implemented in 2017 under the income support system[39]. It incorporates additional support for

[36] Community Visitor of St Helier Care Homes, written notes received 25th July 2017
[37] Community Visitor of St Helier Care Homes, written notes received 25th July 2017
[38] Professor Johnson report, Appendix one
[39] Law drafting instructions "Flexible Care Component", August 2016

low income individuals who receive a care package in their own home but who have care needs below the level at which they would qualify for the LTC Scheme[40].

Although the component falls under the income support system, it is completely separate to the assessment process for personal care components 1 to 3. In order to be eligible to claim the flexible care component, an assessment is carried out by an appropriate health and social care professional under the same mechanism as the LTC assessments.

The Panel referred to this as a two tier system during the Public Hearing with the Social Security Minister:

> **Deputy G.P. Southern:**
> *"But now you have got a 2-tier system still operating from now, one which goes down to £150 a week or thereabouts with the flexible care scheme assessed by social workers, you have got another scheme still in existence, the personal care elements 1, 2 and 3 up to £150. The difference is that that is assessed by a different form using different officers and while you have a need for support, you do not have to spend it on support; you can spend it on whatever else you choose. You have got 2 different schemes abutting each other; do you know whether the people below £150 should not be involved? Has anybody done a check to see if personal care 3 does abut flexible care, which takes you a bit higher or not? Secondly, you have got 2 benefits, one of which must be spent on an approved care package and the other one need not be."*
>
> **Policy Director:**
> *"Okay, very quickly. Not only do we have those 2 benefits, we also have incapacity benefits within our social security scheme. We have long-term incapacity, short-term incapacity and various other things. You are absolutely right, you would not start from here, would you? We are going to have a blank piece of paper, right, we are starting or if you are looking at incapacity from scratch, this is part of our big Social Security review and we are going to have a look at incapacity and say: what is the role of government in supporting working-age people with incapacity, just work-age group to start with and how should we support them with financial benefits, with non-financial support? That will encompass. That work is starting in the background at the minute quite slowly. It will be a dominant part of our work for next year, so there is not really very much to talk to you about today but next year there will be a lot more to do, so it will be part of our Social Security review. That review will look at: is there is a future role for personal care components? How do they link up with long-term incapacity, short-term incapacity? What is possibly the best way of doing it? It is likely to be all different anyway in the future."*[41]

KEY FINDING 8: The flexible care component has been introduced to provide financial support to individuals who have care needs below the level at which they would qualify for the LTC Scheme. Although the flexible care component is part of the Income Support system, the assessment process is undertaken under the LTC mechanism thereby creating a two tier system.

<u>HSSD Policy on funding adults assessed as having complex long-term care needs (policy 2)</u>

Beyond level 4 (the highest level) of the LTC Scheme there is a policy on funding adults assessed as having complex long-term care needs. Essentially, where long-term care funding is insufficient

[40] Draft Income Support (Amendment No15) (Jersey) Regulations 201 – Lodged 3rd April 2017 (P.23/2017)
[41] Public Hearing with the Minister for Social Security, 18th September 2017, p.45

to cover the total cost of an individual's care package the Health Department is responsible for "topping up" the funding[42].

The decision on identifying the most appropriate care package for the individual and the level of additional funding provided by the Health Department is made by a "HSSD Individual Packages and Placements Panel" [43].

The Panel asked the Health Minister to explain the rationale for introducing a system whereby those who have the highest long-term needs and those who have lower level long-term needs fall outside the Scheme:

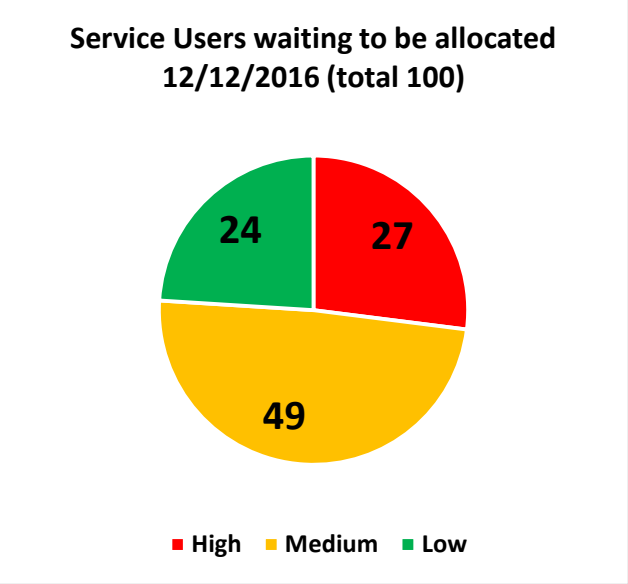
> **The Minister for Health and Social Services:**
> *"For me, I just saw it as bridging that gap between the top of the income support scheme and the beginning of the long-term care scheme. There was definitely a gap, there was definitely a need, and that is why we came out with that one. The other one at the top end, why do we top it up, I was not party to when this came in but I presume this was because if the fund paid everything it would be totally unsustainable, so it was accepted that Health would pick up very complex cases and top it up so the person was not left vulnerable".*[44]

KEY FINDING 9: The LTC Scheme does not cover all care needs. Those who have assessed long-term care needs which fall above the qualifying level for the LTC Scheme are part funded by the Health and Social Services Department. Those who have long-term care needs which fall below the qualifying level for the LTC Scheme are funded by the flexible care component of income support. The different systems create uncertainty over the sustainability of funding streams.

Resource and Manpower

When the LTC Scheme was first implemented there was an increased demand on the Adult Social Service to complete assessments in order to process appropriate care packages for people wanting to join the Scheme. On average these increased from 20 per week in 2014 to 26 per week in 2016[45].

This resource pressure was perhaps heightened by the prioritisation of resources to the "Hospital Discharge Team" so that social workers could assist with patient flow and hospital discharges. However this resulted in a back log of initial low to medium level referrals creating a waiting list of, on average, 100 clients[46].



Due to the backlog of referrals, only those in the high category were being allocated under the LTC Scheme. This resulted in cases that had been identified as low or medium priority to

[42] HSSD Policy on funding adults assessed as having complex long-term care needs
[43] HSSD Policy on funding adults assessed as having complex long-term care needs
[44] Public Hearing with the Minister for Health and Social Services, 19th September 2017, p.29
[45] Quality Improvement Team Case Study – Long-Term Care, Department document accessed 29th August 2017
[46] Quality Improvement Team Case Study – Long-Term Care, Department document accessed 29th August 2017

experience long waiting periods[47]. When the Panel asked the public (and voluntary and community sector) to submit their views and experiences of the Scheme, access and waiting times were a common theme:

> *"Scheme was launched before it was adequately staffed. Although waiting times have improved some people are still experiencing difficulties with delays and lack of communication"*
>
> *"Overall the LTC system is good, but there have been difficulties accessing the Scheme and understanding how it works"*
>
> *"Delays in accessing the Scheme have a financial effect – particularly if people don't have any savings"*
>
> *"There is a long wait between requesting an assessment and the involvement of a Social Worker"*
>
> *"When a social worker does appear, they are very kind and considerate people, but the waiting list for referrals is most unacceptable"*
>
> *"A lack of social workers can hold up the whole process"*

KEY FINDING 10: When the LTC Scheme was first implemented, individuals who applied to join the Scheme experienced delays getting assessed and consequently receiving appropriate care packages. The Panel understands that the system has now improved in terms of waiting times.

Number of Social Workers

The table below provides information on the number of social workers in each area within the service and the number of vacancies as of February 2018[48]:

Area	Permanent & Fixed Term Staff		Vacancies
Adult Services	30		2.3 (7.2%)
Children's Services	48		24.2 (28.5%)
Older Peoples Services	3		2.0 (33.3%)
Total	**81**		**28.5 (23.3%)**

The Panel asked the Health Department to provide the number of social workers who left their posts from January 2017 to January 2018:

- Adult Services: 3
- Children's Services: 11
- Older Peoples Services: 2

The Panel note that there is one agency social worker in adult services and three in older people's services. Although social workers within the children's service do not undertake long-term care assessments it is worth noting that there are 34 locum social workers which includes manager positions and two Interim Heads of Service social work positions[49].

[47] Quality Improvement Team Case Study – Long-Term Care, Department document accessed 29th August 2017
[48] Information provided by the Health and Social Services Department, 26th February 2018
[49] Information provided by the Health and Social Services Department, 26th February 2018

In addition to these figures the Panel asked the Department to provide the number of social workers specifically carrying out assessments for the LTC Scheme. The Department said:

> *"The Adult Social Care Team has 14 FTE Social Workers that complete assessments of need, a proportion of which include LTC aspects. The older adult community mental health team are established for 5 FTE social workers posts. Currently there are four posts filled (two of which are permanently recruited to posts, and two are currently agency staff pending recruitment permanently. They are assigned to complete assessments of need and provide ongoing care management support, of which a proportion included LTC aspects[50]."*

During a Public Hearing the Panel questioned the Health Minister on the figures and whether inconsistencies could arise in assessments due to the numerous turnover of social workers.

> **The Minister for Health and Social Services:**
> *"…..I am concerned about the number of interims that we have and the fact that when people build up a relationship with a social worker, be it one that assesses them or be it one that they work with for their care generally, that relationship is severed whenever there is a change. That is not good. But it is not a conscious decision of ours to not fill these posts. We are desperately trying to fill the posts. We are fishing in a very small pool I am advised. However, we continue to do our best."*[51]

This issue of building up a relationship with social workers was also highlighted by Jersey Cheshire Homes and Autism Jersey:

Jersey Cheshire Homes:

> *"We had a meeting with Social Services and the hospital team on 2 July 2015 and all this came up in that conversation, including the idea of having a single social worker responsible for the Cheshire Home so as we would build a relationship up with that social worker and they would know the sort of things that our residents needed and so on. It seemed a logical and sensible idea and it was agreed with but it has not happened".*[52]

Autism Jersey:

> **Senator S.C. Ferguson:**
> *"But the social worker ... are you having problems with continuity of social workers?"*
>
> **Chief Operations Officer, Autism Jersey:**
> *"Yes. Do you remember I said about the young man who came back from the U.K.?"*
>
> **Senator S.C. Ferguson:**
> *"Yes".*
>
> **Chief Operations Officer, Autism Jersey:**
> *"Well, he had a social worker, he worked with him all the time he was in the U.K. Within 2 weeks of him coming back to Jersey, massive transition, that social worker had been moved off. So then he got a social worker who came over on a 6-month contract, did not actually survive the 6 months and then left. This is support for a young man who has gone*

[50] Email from Director of Ministerial Support and Policy, 18th September 2017
[51] Public Hearing with the Minister for Health and Social Services, 19th September 2017, p.3
[52] Public Hearing with Jersey Cheshire Homes, 24th July 2017, p.8

through a massive change in his life, still is going through a massive change in his life, and he is now on his fourth social worker in less than 2 years."[53]

KEY FINDING 11: The turnover of social workers has meant that clients (and families) have been unable to build close working relationships with their social workers which has contributed to a lack of continuity within the service.

RECOMMENDATION 9: The Health and Social Services Department should ensure that there is a dedicated social worker for each client on the LTC Scheme. This would ensure a continuity of care across the board and ensure that strong working relationships can be formed with each client. This should be implemented by Q4 2018.

RECOMMENDATION 10: Where care is being provided in a care home, the Health and Social Services Department should ensure that there is a permanent link of one social worker to ensure continuity. This should be implemented by Q4 2018.

[53] Public Hearing with Autism Jersey, 24th July 2017, p.18

8. Respite Care and the Long-Term Care Scheme

The Health Department explained that the assessment includes a section around carers' needs and ongoing carer support. The assessment evaluates the need of the individual being cared for and then the care and support they receive on an informal basis by their carer. This then allows a "sustainability allowance" to be built into the resource allocation – effectively a period of respite[54]. The Panel was informed by the Social Security Department that a carer may be able to receive up to 6 weeks respite per annum.

The Panel heard evidence from a number of stakeholders and members of the public who said respite care under the LTC Scheme was problematic. One such submission was from the Jersey Alzheimer's Association (JAA) who raised concerns around accessing respite beds:

> **Jersey Alzheimer's Association**
> *"There seem to be significant problems for people wishing to access temporary, respite care so a carer can have a break from caring while a relative is cared for in a care home, or if the carer needs to go into hospital themselves or becomes too ill to care for a while. Health and Social Services previously administered a respite budget, which was available for such care and allocated at the discretion of a Community Psychiatric Nurse or Social Worker. While this was not always equitable it usually meant that people could access respite when they needed it or if they booked it in advance. Now that respite care is a component of the LTC budget, people have to be in the LTC scheme to access respite care. Often the need for respite is urgent and unplanned and may be necessary for people not yet needing regular, high level care, who have not joined the LTC scheme.*
>
> *Further to this, our clients report that finding care homes with respite beds is virtually impossible, as increased demand for permanent care home beds has limited the number that care homes keep for respite only. Obviously, as a business it is easier to have a room permanently occupied with revenue thus maintained, as the room is never unoccupied.*
>
> *Carers frequently report to me that they feel uncared for by 'the system' and that the only support they feel they have available to them is provided by JAA. There seems to be no provision in the LTC scheme for carers, apart from the (problematic) respite component described above"*[55].

The Panel also found that there are continuing questions about access to respite care. It appears that some are content with the respite they receive, whilst others struggle to gain access particularly when urgent or unplanned.

> **Submission 6:**
> *"I was lucky enough to get some Respite Care, apparently it is a bit of a lottery, so now and again Mum went to [a Residential Home] for a long weekend".*
>
> *"On one occasion the respite was cancelled due to a virus at the home, fair enough, but when I asked when it would be re-arranged, shock, horror, greeted these words and I was made to feel like Oliver Twist. At the time this reduced me to tears and it was sorted by another member of the departmental staff."*[56]

[54] Public Hearing with the Minister for Health and Social Services, 19th July 2017 p.41
[55] Written Submission by Jersey Alzheimer's, received 13th April 2017
[56] Written Submission 6, Private, received 2nd February 2017

Mrs L. Bratch, Enable Jersey:
"As we have said before, for many reasons it is not always possible for families to keep their loved ones at home. We have found that under-65s respite is a particular problem because of a lack of availability. This problem is well known and was highlighted by families attending the recent Carers Strategy Day. Respite was highlighted as a priority within the Strategy. It should be easily accessible, flexible and tailored to the individual's needs. Listen to the families and give them control over their lives. For example some people may be quite happy receiving respite in their own home. However, on a personal basis I do not find this to be a true break with support staff coming and going all the time. We still have the feeling of responsibility with our young person at home. It is not the same. And it's not the same for the young person either as they do not get to have time away from home and mix with their friends. They need to develop their confidence and independence because, you know, with the best will in the world we are not ... and other families are not always going to be able to be there for them. Having said that there will be people who will be saying respite at home is absolutely what they need and absolutely what their loved one needs. So as we have said one box does not fit all because we are all different".[57]

The Panel notes that the "LTC General Information" leaflet provides an explanation of the Scheme and the different LTC benefits people can claim if they are eligible. However, the leaflet does not mention respite care, and how to claim it in any of the sections. This is particularly relevant to note as the Social Security Department explained that it was possible to apply for the Scheme purely to receive respite care in circumstances where a family member is giving care and thereby not receiving any funding from the Scheme:

Deputy J.A. Hilton:
"What happens if where you have, say, a retired couple and one is receiving care from their partner in their home but they are not accessing the Long-Term Care Fund? I presume that the Social Security have not got a budget to offer the carer respite in those circumstances".

[…]

Policy Director:
"But that is believing the spouse is providing all the care; the spouse is allowed to have time off as well, so I mean they can still ask for long-term care and just use the money to get respite from it; it is perfectly okay"[58].

The Panel is unclear as to how this process works in practice, particularly when a couple, for example, require respite but do not have sufficient funds in the time period before they are eligible to receive the LTC benefit. Although property loans may be an option to fund respite care, whether or not someone is able to apply for one is dependent on a range of criteria. The Panel hope that this provision is made clear to individuals by the LTC Team within Social Security.

KEY FINDING 12: A group of carers are receiving respite care which continues to be funded by the Health Department. However, it is possible for people to access the LTC Scheme purely to receive funding for respite, although some carers will need to pay for care whilst respite is provided to them. This differs from the previous arrangements where all respite was provided at no charge to carers.

[57] Public Hearing with Mrs. L. Bratch, Enable Jersey, 26th July 2017, p.12 - *note that the quote was updated by Mrs Bratch on 22nd February 2018*
[58] Public Hearing with the Minister for Social Security, 18th September 2017, p.48

KEY FINDING 13: The LTC General Information Leaflet offers no explanation on the options for respite care.

RECOMMENDATION 11: The Social Security Department and Health and Social Services Department should make it better known that people can access the LTC Scheme purely to receive an allowance to use for respite care. This should be undertaken in various ways but should include a full explanation on the options for respite care within the LTC General Information Leaflet, or by producing a standalone leaflet on respite care by Q3 2018.

There is an existing group of adults with learning disabilities and/or on the autistic spectrum who, along with their carers, receive respite care and who are not on the LTC Scheme. The Health Department holds a budget of £521,000 (2017) to fund this respite care. In 2017, this funded 32 adults and will be fully spent, as it was in 2016[59]. It is unclear whether this group of adults will be advised to access the LTC Scheme, but the Panel was informed that any new carers requiring respite care would need to apply for the LTC Scheme, if the person they are caring for was eligible.

The Panel considers that respite care should be highlighted as a fundamental issue within the Health and Social Care system as a whole. As the Jersey Carers Strategy (2017) explains "*society owes a great deal to the thousands of people who provide unpaid care and support to a family member or friend. The pressure on many carers is often high and the impact on their lives is significant*"[60]. The Strategy identified that the need for enough appropriate and high quality respite is considered a significant issue currently and there is a powerful message from carers that flexibility and personalisation are key to bridging this gap[61].

KEY FINDING 14: Access to respite care through the LTC Scheme is a fundamental issue. Some people struggle to gain access to respite, particularly when urgent or unplanned. Present arrangements do not meet needs in many cases which risks the provision of care within families.

KEY FINDING 15: Carers make a significant contribution to society by providing unpaid care and support to their loved ones. The pressure on many carers is often high and the impact on their lives is significant, thereby highlighting the importance of sufficient respite provision.

RECOMMENDATION 12: Both the Minister for Health and Social Services and Minister for Social Security should carry out a detailed review of respite provision and its funding. The review should include all aspects of Priority 1 within the Carers Strategy 2017 ("Getting the right Respite"). The outcomes of the review should be reported back to the States before the end of 2018.

[59] Email from the Health and Social Services Department, received 23rd October 2017
[60] Jersey Carers Strategy, June 2017, para 3.0
[61] Jersey Carers Strategy, June 2017, para 6.1

9. How care is provided under the Long-Term Care Scheme

Once an individual has been assessed to receive the LTC benefit, care might either be provided in their own home or in a care home depending on their care needs.

Standards of Care

If individuals receive care in a home, it has to be registered under the Nursing and Residential Home (Jersey) Law 1994 and approved under the Long-Term Care (Jersey) Law 2012[62].

If individuals receive a package of care in their own homes, to be covered by the LTC Scheme, this has to be delivered by a care provider on the Health and Social Services' approved provider list[63]. Individuals are not able to select and pay a care giver who is not on the approved provider list. It is possible, however, to register under the LTC Scheme and to receive care from a family member as long as he/she is unpaid.

The approved provider list includes organisations that provide domiciliary care for the elderly as well as organisations who specialise in caring for adults with long-term conditions and disabilities.

It is understood that once the Regulation of Care Law comes into force, the approved provider list will cease because care providers will need to register and meet standards under the regulatory regime.

Regulation of Care Law

The Regulation of Care Law provides a framework for the regulation of health and social care in Jersey. Even though the Law was adopted in 2014, it cannot come into force until there are Regulations describing what services will be regulated and what those services must do to ensure the care provided is safe and of high quality[64]. It is understood that the Regulations will be lodged and debated in 2018.

Ethical Care Charter

In July 2017, an in principle decision was made by the States Assembly to develop a Jersey Ethical Care Charter[65]. The Charter is due to be lodged by the Health Minister in 2018 following a public consultation. It is anticipated that the Charter will recommend that all providers of domiciliary care should meet a certain set of standards, such as; travel time for carers; client visits based on need rather than being time focussed; and a clear procedure for staff concerns. It is also anticipated that care providers will be encouraged to sign up to the Charter, although the legal status of the Charter is yet to be decided.

The implementation of the Regulation of Care Law and the Jersey Care Commission is to be welcomed. The Jersey Care Commission will oversee the quality of care provided to individuals either in their own homes or in care services (including care homes)[66], which should give the

[62] Jersey Long-Term Care Leaflet, March 2017, p. 8
[63] Jersey Long-Term Care Leaflet, March 2017, p. 8
[64] Regulation of Care (Jersey) Law 2014 Draft Regulations for Care Homes, Care at Home and Adult Day Care Services
[65] P.48/2017
[66] Information accessed at https://www.gov.je/news/2017/pages/carecommappt.aspx

assurance of high standards and cost efficiency. A future Scrutiny Panel may undertake separate scrutiny of the Regulations which will underpin the Law but at present the Panel would make the point that, in hindsight, the Law and its Regulations should have been implemented at the same time as the LTC Scheme. This would have ensured that care providers were under a legal obligation to provide appropriate care.

KEY FINDING 16: The implementation of the Regulation of Care Law and the establishment of the Jersey Care Commission are to be welcomed. In hindsight, the Law and its Regulations should have been implemented at the same time as the LTC Scheme, which would have ensured that care providers were regulated to provide appropriate standards of care.

Delivery of Care

During the review the Panel identified a potential risk regarding care fees. Potentially a care home could increase its fees beyond the maximum payable under the LTC Scheme at any one time. For example, a care home could increase the co-payment required from residents by 10% above the rate of inflation and there is no mechanism in place to monitor or cap care fee levels. The result of this might be that the LTC payment might lag behind the fees charged by the care home and that individuals needing care might be unable to meet extra costs required thereby putting pressure on the LTC Scheme to keep pace. This might lead to a vicious cycle of increasing costs and taxpayer funding being the only resource to meet increasing costs.

This concern was also raised by the Jersey Alzheimer's Association who said that as long as care is provided by businesses, limited by the approved providers list, prices for care will continue to rise and the quality of care delivered may be increasingly difficult to regulate[67]. When asked questions around this issue the Social Security Department said:

> **Policy Director:**
> *"You could move to a position where you had adequate accounting, where basically care homes showed you their accounts. Yes, that is one way of doing things. I could say you could set maximum fees, you could have something like rent control for care homes, these are things that we have not had to deal with and we have not looked at specifically because they are not problems we yet have to solve."*[68]

Professor Johnson (Panel advisor) identified this as a potential issue and advised that it would need careful monitoring:

> "*There are continuing questions about the capacity of care providing agencies to deliver good care packages to those at home and for Care Homes to meet high standards. Also the reported increasing of weekly charges introduced by all providers since the Scheme became operational….. A new market in care provision has been created which requires careful monitoring, both for the quality of its staff and services, but also for the charges made to individuals.*"[69]

[67] Written Submission by Jersey Alzheimer's, received 13th April 2017
[68] Public Hearing with the Minister for Social Security, 18th September 2017, p.35
[69] Professor Johnson Report , appendix 1

RECOMMENDATION 13: Since the introduction of the LTC Scheme a new market in care provision has been created. The Social Security Department should monitor the charges made by care homes and report to the States on an annual basis.

Types of long-term care

During the Panel's review it became clear that the LTC Scheme is catering for two main types of long-term care - young adults with long-term conditions/disabilities and older aged adults with chronic long-term conditions. This distinction was also identified by Professor Johnson: "*It is increasingly clear that there are two separate schemes. One for younger people and another for those who are old and frail*."[70]

Young Adults

Young adults with long-term care needs generally fall into three groups - there are those that live at home and are cared for by their relatives, those that live independently with support, and there are those that have moved into group home settings largely provided by Les Amis.

For adults with long-term conditions or disabilities it is important that they are able to access social activities, particularly those that foster social bonds and friendships which help support their quality of life[71]. In a broad context, young adults may need an element of the LTC benefit to support them more in the community compared to older adults who may need their benefit for more health related care needs. The Panel received a submission from a parent of a disabled young adult who was concerned about the practicality of the personal allowance payable under the LTC Scheme (presently £36) and its scope to cater for the social needs of young adults:

> **Submission 2.45**
> *"On a personal basis only, my daughter first joined the scheme in 2015 on moving into a community home. As much as we were grateful for the opportunity that the scheme gave her, my lasting concern was around the personal allowance, which at the time was approximately £32.00* [£36] *per week. Without a supportive family she would not have been able to afford such things as clothing, hairdressers, social and leisure pursuits or holidays. For young people with a lifelong disability who are either unable to work, or who cannot find suitable employment, this allowance is not practical. They deserve to lead a fulfilled and meaningful life...not just survive!"*

Therefore, whatever an individual's care needs are, be it health or social, the Panel considers it important that the LTC Scheme is personalised to the individual. Autism Jersey, who support children and adults with autism, told the Panel that the LTC Scheme can be restrictive:

> **Chief Operations Director, Autism Jersey**
> *"[*The*] long-term care [Scheme] takes away the personalised element of support and takes away the opportunity for people to be able to direct their own support. That is what the world is about. It is about enabling people to add more input in their own lives, to be able to live more fulfilled lives, to be making more informed choices and decisions. Not just about money but about the lives they lead, the employment opportunities that are available to them or not available to them. I just think long-term care can be quite restricted. It is*

[70] Professor Johnson Report, appendix 1
[71] https://www.livestrong.com/article/125884-activities-adults-developmental-disabilities/

very narrow, or it appears to be very narrow. It is very prescriptive about how you can spend the money. Not everybody wants to spend their money in a certain way"[72].

The Panel raised this issue with the Health Department:

The Deputy of St. Ouen:
"In the case of those families who are looking after an adult with learning difficulties, I think the problem is that adult needs support rather than care. That adult is not frail or sick and is in the community. But if that adult moved into the long-term care scheme, he would only receive something like £35 [£36] *a week to meet his living costs. That is the pocket money element of long-term care, I understand. If he is in the community and he wants to go out to the cinema, go to the pub, very often they have a support worker with them that just is not sufficient to provide enough support financially, it seems to me."*

The Minister for Health and Social Services:
"The support is paid for. I understand what you are saying about the pocket money."

The Deputy of St. Ouen:
"Yes. Do you think there should be any flexibility to allow that ...?"

The Minister for Health and Social Services:
"I do think it is worth looking at."

The Deputy of St. Ouen:
"Do we recognise that the long-term scheme has 2 separate groupings of clientele? There are the elderly who need care by reason of their age and frailty, but there are also those with long-term health conditions, perhaps from birth or a very young age. Is there a conflict sometimes?"

Acting Team Leader, Adult Social Care Team:
"I would not go as far as saying there is conflict. There is a great deal of individualisation and flexibility built into the system. However, I agree with the Minister we should never stop looking at ways to be as personalised for an individual, and you have touched on some of the areas of difficulty."

The Deputy of St. Ouen:
"*Has any thinking gone into that or consideration as to what might be done?"*

Acting Team Leader, Adult Social Care Team:
"Direct payments or personal budgets may deal with it but we need to do appropriate exploration…."[73]

KEY FINDING 17: The LTC Scheme caters for young adults with long-term conditions as well as older aged adults with chronic long-term conditions. At present the Scheme fails to provide sufficient personalised care to the individual. The Scheme must be personalised to the individual so that their health and social care needs are met. A young adult may need their LTC benefit to use for more social related activities compared to an older adult who may need their benefit for more health related care needs.

[72] Public Hearing with Autism Jersey, 24th July 2017, p.11
[73] Public Hearing with the Minister for Health and Social Services, 19th September 2017, p.34/35

RECOMENDATION 14: The Social Security Department and Health and Social Care Department should consult with adults with long-term conditions, their carers and the Voluntary and Community Sector which supports them. The purpose would be to better assess the needs of young adults and the ways of meeting those needs. The Department should report back to the States with its findings before the end of 2018.

Group Homes

Les Amis is an organisation who provide residential facilities, outreach and respite services to adults and children. Les Amis provide care within bespoke community based houses (group living) rather than larger 50+ bedded units. The Panel met Les Amis who explained that the current assessment process for the LTC Scheme included a deflator for group living. A deflator is a reduced payment to take account of costs that might be shared between LTC recipients. The Managing Director of Les Amis explained that this added additional pressure on placements if a client had to leave (for example, due to health reasons)[74]. Within the Les Amis care model, one empty bed in a four bedded unit would translate into a 25% reduction in income overall. In contrast, one empty bed in a fifty bedded care home would translate in a 2% loss of income:

> **Managing Director, Les Amis**
> *"So, long-term care, when we look at the economy of scale, if you were going to open a care home, you would open a 40 to 60 bed care home, because this system here would pay for it and you would make a nice profit.*
>
> *We have care homes with 4 people in them. There is no economy of scale. The social care model we have in Jersey is second to none and we should be proud of it, but it is going to cost money"*[75]*.*

In order to further understand this issue, the Panel met with officers from the Health and Social Security Departments. The Director of Adult Services explained that clients living in group homes were assessed on an individual basis but a percentage (deflator) was removed from the overall budget. If a client's needs exceeded the LTC level 4 (maximum level under the LTC Scheme) the Health Department would "top up" their benefit. The Panel was advised that the deflator was only applied to the "top-up" supplied by the Health Department and was not applied to the LTC payment[76].

If a client left a group home, a reassessment of the remaining clients' living situation would normally be undertaken to ensure the group home remained financially viable. The officers highlighted a specific instance where a reassessment had not been undertaken within reasonable time, which they acknowledged had impacted financially on Les Amis[77].

The Panel wish to point out that the States of Jersey is highly dependent on Les Amis as a number of care packages are passed on to the organisation (and other community and voluntary organisations) through a Service Level Agreement. Although the Health Department still provide supported living for adults with learning disabilities, it is mostly in regard to those people with high risk, highly complex needs[78].

[74] Record of Meeting, Health and Social Security Panel, 30th October 2017
[75] Public Hearing with Les Amis, 24th July 2017, p.12
[76] Record of Meeting, Health and Social Security Panel, 9th November 2017
[77] Record of Meeting, Health and Social Security Panel, 9th November 2017
[78] Email received from the Director of Adult Services, 2nd February 2018

KEY FINDING 18: Les Amis have raised concerns about the sustainability of their service due to a deflator added for group homes.

RECOMENDATION 15: The Social Security Department should monitor the situation with Les Amis in terms of the deflator added for group homes and engage with the organisation recognising the importance of the service they provide.

Needs of the Elderly

In his report, Professor Johnson (Panel advisor) also draws attention to the social needs of the frail, elderly group. He says:

> **Professor Johnson:**
> *"The group that needs the greatest attention currently receives the least. Those whom Lynn and Adamson tellingly, but inelegantly, label as experiencing "prolonged dwindling" are the ones whose last lap is often painful and depressing for the individual and exhausting for their (often elderly) carers. It goes on for too long. Confined to the house, and with little to stimulate them, these older people deserve spiritual as well as functional care[79]."*

Professor Johnson recommends that as the LTC Scheme moves into its second stage of operation *"it needs to take more account of the rising population of very frail - often combined with dementia - who are being somewhat overlooked"*[80].

RECOMMENDATION 16: In pursuing a policy presumption that it is preferable to provide care in people's own homes, the Minister for Health and Social Services should ensure there is awareness of the risks of depression and isolation amongst older people. Ways to counteract this should be included within policy.

Income Support and Long-Term Care

The income support system includes an assessment of impairment. The range of medical and health needs supported by impairment components of income support are considered through a separate application and assessment process. The staff who process these claims are employees within the Social Security Department. The assessment process considers both information provided by the individual and evidence from GPs and/or relevant specialists[81]. Impairment components of income support are available to assist with costs as follows[82]:

- personal care components (three levels) provide additional support for individuals who have difficulty undertaking basic daily activities;
- mobility components (two levels) provide support for those who have significant mobility problems outside the home; and
- clinical cost components (two levels) provide additional support for those who need a higher than average number of GP visits to monitor an ongoing medical condition.

[79] Professor Johnson Report, appendix 1
[80] Professor Johnson Report, appendix 1
[81] Written Question by Deputy J.M Macon to the Minister for Social Security, 23rd February 2016
[82] Written Question by Deputy J.M Macon to the Minister for Social Security, 23rd February 2016

The Panel heard of some cases where, prior to accessing the LTC Scheme, an individual received income support which included the personal care component (level 3). Particularly for families supporting a young person with complex needs, the personal care component (a weekly sum of money) could be spent on social activities, petrol or meals out. Since the LTC Scheme was implemented, some individuals applied for the Scheme but were unaware that the personal care component would cease. Under the LTC Scheme, there is nothing that specifically replaces the personal care component and all benefits have to be paid to an approved provider. Therefore families no longer have the flexibility to spend the personal care component on anything they choose if they are the ones providing most of the care:

> **Acting Team Leader, Adult Social Care Team:**
> *"…..of course they are inherently different, as you rightly said, in that one is a cash benefit, the expenditure of which is not cross-checked, if that is the word. The other is a benefit that is safeguarding directly for the provision of care from the approved provider framework. There is an element of choice in that so I am not entirely surprised that you have come across people: "You are getting P.C.C.3 (personal care component 3) but I think you are eligible for long-term care" and they may well be".*
>
> **Deputy G.P. Southern:**
> *"But they might turn it down because the support network that they have, the family around them, treat that piece of income as that income which helps us cope and were they to apply for long-term care that would then be directed to suppliers of assistance rather than the family".*
>
> **Acting Team Leader, Adult Social Care Team:**
> *"Currently only approved suppliers can be ..."*
>
> **Deputy G.P. Southern:**
> *"Yes, absolutely, so they would see that as a reduction in their income and a worsening of their situation even though one of the problems was dealt with more effectively by the long-term care scheme".*
>
> **The Minister for Health and Social Services:**
> *"I have spoken to families in that situation and it then needs to be made very clear that if they are not going to take that level of support, the long-term care that they would be better off staying where they were."*
>
> [….]
>
> **The Minister for Health and Social Services:**
> *"However, they could, and I know of families that have, asked for an assessment and then when they weigh it all up they are better to stay where they are for the time being".*[83]

This issue was raised by a parent caring for her son who has complex long-term care needs [note some of the submission has been redacted to protect identities]:

> *"We are now in the process of our son going to be receiving respite care through Autism Jersey shortly. Because Autism Jersey are a provider of service we have been told that his respite would have to go through the Long Term Care Scheme.*
>
> *We are resisting this due to the following:*

[83] Public Hearing with the Minister for Health and Social Services, 19th September 2017, p.32/33

Our son would lose his care component from his Income Support to the value of £145pw leaving him with the standard amount for an adult on Income Support which is £92.12.

With Autism Jersey taking over our son's respite we would still have to pay for all of his outings / meals out costs / petrol for car being supplied which would be impossible with the £145pw reduction.

At present the extra £145 pays towards all of our son's outings / meals out costs / petrol / replacing communication devices that he breaks often / replacing or repairing items in the house that he breaks / toiletry items that he still needs.

Due to our son needing constant supervision and at least a 2-1 ratio of support with Autism Jersey, his care package will exceed the amount payable from Social Security and would then have to go to the high cost panel at health every time he will need his hours increased as he ages.

We are finding it hard to understand why respite service is even included in the Long Term Care scheme. We as a family care for our son 24-7 and are only asking for 15 hours a week respite for our son. When he was in respite at XXXXX he was receiving 35 hours a week care which was going to be increased to 49 hours per week. To then be told that for our son to receive 15 hours per week he will then loose the £145pw from his Income Support is a slap in the face to us for caring for him.

We wouldn't mind as much our son losing the £145pw if Social/Health look into the fact that his care package should then include the extra costs involved (i.e.) outings / meals out / petrol for his transport / replacing and repairing items and communication devices so that we would not have to incur these costs ourselves. The benefit of doing this is that then our son would remain at home for longer which in turn would save the States. We are well aware of the cost to the States of our son going into full time care and also the size of a care team it would take to care for him.

Yes we do receive a carers allowance for our son which is a 4 weekly payment of £816, which you have to care for someone for a minimum of 35 hours a week to receive. This sum equates to an hourly rate of £5.83 over a 35 hour week which is well below the minimum wage. Also taking into effect that our family cares for our son well over 35 hours a week, social security are getting a very cheap service of care from ourselves considering they pay care providers £970pw for the highest care level, which our son would be under in the long term care scheme.

We will not agree to move our son's care to LTC until Social / Health look into the matter of the extra costs involved in looking after our son and giving him a full active life out in the community"[84].

KEY FINDING 19: Once an individual has applied for the LTC Scheme, if they are receiving income support, the personal care component is no longer payable. Instead only a small amount for personal expenditure is payable under the LTC Scheme. Therefore individuals no longer have the flexibility to spend the sum of money they receive as the personal care component on living in the community, if their families are the ones providing most of the care.

[84] Written Submission 2.39, received 19th April 2017

The Panel raised a concern regarding how assessments were undertaken, and by who, for receiving the personal care component (level 3) and levels 1 - 4 under the LTC Scheme. Both assessments are carried out differently and are based on different criteria:

> **Deputy G.P. Southern:**
> *"……Have you done any check that one set of assessments at the bottom end matches the assessment that you do going upwards, because that is important? I have certainly seen people on personal care 3 that needed significant amounts of help just to function. They were getting it from their family, but I would have thought that is looking to me like long-term care. Where are you there?"*
>
> **Acting Team Leader, Adult Social Care Team:**
> *"There is quite a lot there in what you said. We have certainly looked with our colleagues in Social Security about ways to make this more efficient in terms of particularly when we are assessing people and they are not meeting the criteria for long-term care, it does not feel completely right that that person has to start again in applying for a benefit. I think we have certainly looked at how we might, and we continue to look at how we might, with people's consent, give that information directly to Social Security to make the process more efficient".*[85]

KEY FINDING 20: The assessment to find out if an individual is eligible to receive the personal care component of income support is undertaken differently and based on different criteria compared to the LTC assessment. Therefore, in some cases it may be more appropriate for an individual to receive the LTC benefit rather than the personal care component of income support.

KEY FINDING 21: There is a risk that vulnerable adults will not receive the care they need because within their families a decision is made not to apply for the LTC benefit, choosing instead to retain a personal care component of income support which they consider essential to provide for the needs of that adult living in the community.

[85] Public Hearing with the Minister for Health and Social Services, 19th September 2017, p.31

10. The Financial Health of the Long-Term Care Scheme

The Panel's advisor, BWCI, explained in its report that the LTC Scheme has only been fully operational in the post-transitional state since January 2016. Therefore there is limited experience to assess whether the LTC Scheme has reached a stable state in relation to the proportion of claimants in each care level.

IT System

When requesting various statistics from the Social Security Department, BWCI were advised that the Department was in the process of upgrading its LTC IT administration system. In that regard, BWCI were not able to review the new system's data reporting capabilities but did review the data that was available based on the older system (it is not thought that the differences are material). BWCI recommend that the Panel reviews whether the functionality of the new IT system will be able to record and report on[86]:

- The numbers of claimants in each care level at a given point in time
- How long a claimant spend in each care level and
- The progression of a claimant through the care levels

BWCI also recommend that the Panel considers whether the financial information provided to claimants will be fit for purpose once the new report tools in the new IT system are fully functional[87]. The Panel note that this may be an issue for the next Health and Social Security Panel.

Data

BWCI note that there is a lack of data available to determine how long claimants are expected to remain at a particular care level or the pattern of progression between care levels. Collecting this data will be important when considering what assumptions are most appropriate in any future modelling of projected costs[88]. BWCI recommend that statistics about the proportion of claimants in each care level and the transitions between levels should be monitored and published as part of the Social Security Minister's annual report.

It is noted that the previous Panel's review (S.R.11/2013 "Long-Term Care Scheme") made two recommendations in relation to this issue:

> **Recommendation 1** - Improved data on the average duration of long-term stay specific to Jersey should be gathered and maintained.
>
> **Social Security Minister's Response:**
> *"Agreed. There is no comprehensive data set on length of stay in Jersey. As such, UK data – based on research completed by the Personal Social Services Research Unit (PSSRU) on length of stay in BUPA care homes – was used, and is a good benchmark in the absence of comprehensive Jersey data.*

[86] BWCI Report, Appendix 2
[87] BWCI Report, Appendix 2
[88] BWCI Report, Appendix 2

With the introduction of the LTC scheme, SSD will be able to gather length of stay information. Investment in community-based services to reduce the demand for long-term care is part of both health policy P.82/2012 and LTC policy P.99/2013"[89].

Recommendation 2 - Regular analysis of Jersey-specific data relating to the duration of long-term stay should be carried out in order to monitor and assess the cost implications of the Long-Term Care Fund and its financial condition. This should not only be included in the Department's actuarial review, but also reported to the States on an annual basis.

Social Security Minister's Response:
"Agreed. The information on duration of long-term care will be required to inform the regular actuarial reviews of the LTC Fund. The Social Security Reports and Accounts (2014) will incorporate key information pertaining to the LTC Fund, such as average duration of long-term care claims".

BWCI advised that it was not possible for the Social Security Department to provide them with any information regarding the average length of LTC claims, the numbers transitioning between care levels each year or the number of deaths. Although these recommendations were agreed by the Minister in 2013, it does not appear that they have been implemented.

KEY FINDING 22: Although in 2013 the Social Security Minister agreed to report annually on certain key statistical information, this has not happened. Collection and reporting of this information is important in considering assumptions in any future modelling of projected costs.

RECOMMENDATION 17: Statistical information about the proportion of claimants in each care level and the transitions between levels should be monitored and published as part of the Social Security Minister's annual report.

The Ageing Population

The Jersey Health Profile 2016 explains that life expectancy at 65 has increased among both men and women[90]. Around the time the LTC Scheme was being proposed, the ageing population was cited as one of the reasons why a Scheme was needed: "*Jersey faces a large increase in both the number and proportion of older residents over the next 30 years. An ageing population means more people will need long-term care, and costs are predicted to more than double by 2044*"[91].

The proportion of the population over the age of 65 demonstrates that Jersey's population is ageing. By the end of 2035 nearly a quarter of the population is expected to be aged 65 or older and at the same time, the working age (defined as aged 16 - 64) population is falling[92].

[89] Ministerial Response to S.R.11/2013 presented to the States on 4th December 2013
[90] Jersey Health Profile 2016, Data for 2013 – 2015, Public Health Statistics Unit, Public Health Strategy Unit, p.45
[91] Factsheet "About the proposed long-term care scheme" accessed December 2017
[92] BWCI Report, Appendix 2

As at 31st December 2015 the ratio of the non-working age population to the working age population was 50%. BWCI explains that this ratio will change over time if the proportion of people of working age changes relative to the total population: *"The higher the dependency ratio the fewer people of working age there are in the population to support those who are over pension age. An increasing dependency ratio is expected to increase financial pressures on the LTC Scheme"*[93].

BWCI carried out an analysis of the ageing population in relation to LTC claimants. Data provided by the Social Security Department (as of 31st May 2017) showed that 80% of the 1,200 claimants were aged over 65 and that there is a correlation between age and long-term care needs. The need for care is greatest amongst those aged 85 and over[94].

BWCI concluded that:

> *"The interaction of a changing demographic profile with changes in income and assets over time means that it is difficult to predict how the financial position of the LTCS will develop over the next 20 years. However, if it is generally assumed that the next generation of pensioners requiring care will have less assets than the current generation, there could be an increase in demand for LTC Support".*[95]

BWCI recommend that information about the assets of those entering care should be recorded, so that any trends in the amount of these assets can be monitored. This information could be of assistance in any future modelling of the LTCS.

KEY FINDING 23: The financial demands on the LTC Fund are likely to increase if the next generation of older adults requiring care has fewer assets than the current generation.

RECOMENDATION 18: The Social Security Department should ensure that information about the assets of those entering care is recorded, so that any trends in the amount of these assets can be monitored. This information could be of assistance in any future modelling of the LTC Scheme. The appropriate processes should be put in place by Q3 2018.

Care Needs

BWCI note that changes of care needs could also have implications for the financial stability of the LTC fund. For instance, the nature of their health issues will determine the length of time a claimant stays in care. Professor Johnson makes reference in his report (p.55 appendix 1) that in the UK there has been a marked growth of dementia deaths and a shift in the places where people die. Although Jersey statistics do not reflect the same level of dementia deaths (cancers are the main cause of death locally[96]) people living with dementia often experience "prolonged dwindling"[97] deaths preceded by longer stays in long-term care. Professor Johnson explains that it is possible that disease patterns in Jersey differ significantly from those in England or there may be a different practice in recording the cause(s) of death on death certificates. He comments further:

[93] BWCI Report, Appendix 2
[94] BWCI Report, Appendix 2
[95] BWCI Report, Appendix 2
[96] Health Profile 2013 - 2015, published in 2016, p.58
[97] Professor Johnson report, Appendix 1

Professor Johnson

"A new report from Public Health England, Place and cause of death for permanent and temporary residents in care homes, (October 2017) reveals that "…taking into account those for whom dementia was the underlying cause of death (31%) and those for whom it was a contributory cause, the number who died with dementia can be estimated as high as 62%". It is inconceivable that these rates are not replicated on Jersey".[98]

BWCI recommend[99] that any anticipated changes in care needs over time, as a result of medical advances in the treatment of diseases and conditions of the elderly, be factored into the model to project the LTC Scheme's financial sustainability.

RECOMMENDATION 19: Any anticipated changes in care needs over time, as result of medical advances, should be factored into the model to project the LTC Scheme's financial sustainability.

RECOMMENDATION 20: The Panel's advisor notes that in the UK there has been a marked growth of dementia deaths. The incidence of dementia in Jersey and the recording of causes of death should be researched further in the interests of statistical accuracy and future modelling. The outcome should be reported to the Panel by Q3 2018.

Contributions

In 2016, the LTC contribution rate increased from 0.5% to 1%[100]. The Social Security Minister has advised that the LTC contribution rate will need to increase steadily over the next two decades to ensure that the LTC Fund can sustain the increase in benefit expenditure due to the ageing demographic[101]. The Minister has stated that there is currently no intention to increase the contribution rate before the end of 2018[102].

In addition to contributions from taxpayers, the States also pays an annual grant to the LTC Fund. In 2016, the States Grant to the Fund amounted to £34 million, comprising of a £6 million transfer from underspends in 2015 and a tax funded grant of £28 million. The value of this grant will rise in following years in line with the annual increase in RPI[103].

KEY FINDING 24: The contribution rate to the LTC Fund will need to increase steadily over the next two decades to ensure that the Fund can sustain the expected increase in benefit expenditure caused by the ageing demographic.

Income and Expenditure

The table below summarises income and expenditure levels for the LTC Fund as at 31st December 2016[104]:

[98] Professor Johnson report, appendix one
[99] Section 8.3
[100] R.92/2017 "Ministers Report 2016" Social Security Department, published 24th July 2017, p.18
[101] Written Question to the Minister for Social Security by Deputy S.Y. Mézec, 18th April 2017
[102] Written Question to the Minister for Social Security by Deputy S.Y. Mézec, 18th April 2017
[103] R.92/2017 "Ministers Report 2016" Social Security Department, published 24th July 2017, 2017 p.19
[104] R.92/2017 "Ministers Report 2016" Social Security Department, published 24th July 2017, p.10

	**Long-Term Care Fund £ Million**
Income	52.4
Expenditure	43.6
Surplus	8.8
Net Assets at 31st December 2016	20.0

The Social Security Department has projected that in 2017 the LTC fund is expected to have a surplus of income over expenditure in excess of £5 million[105]. BWCI explain that due to the expected growth in the LTC benefit and LTC Support payments, income and expenditure are expected to be broadly in balance in 2018. In 2019, however, the Department forecasts that the fund will move into a "net cash consuming" (shortfall) position. The Budget 2018 explains that a balance has been built up (using underspends) to allow time for the States to consider changes to the level of the contributions needed to ensure sustainability of the fund in the long term[106].

The Panel notes that although BWCI highlight a number of potential areas where improvements could be made, they have no concerns about the financial stability of the LTC Scheme at this stage. However, the LTC Law requires the Minister to appoint an actuary to report on both the financial condition of the LTC Fund and the adequacy of the contributions being paid in. It is understood that the Minister intends to commission an actuarial review in 2018. BWCI recommend that a formal timeline is set for the first actuarial review of the Scheme. BWCI also recommend that the review should include an analysis of actual experience to date which could then be used as the starting point for determining realistic assumptions for the future financial modelling of the Scheme.

RECOMMENDATION 21: As recommended by the Panel's advisor, BWCI, the actuarial review of the LTC Fund being conducted in 2018 should include an analysis of actual experience to date. The Social Security Department should use this as the starting point for determining realistic assumptions for the future financial modelling of the LTC Scheme.

[105] BWCI Report, Appendix 2
[106] Budget 2018, p.136

11. Addendum Recommendations

During the Panel's review, a number of submissions highlighted issues relating to the LTC Scheme. Although the Panel has provided for most of the major issues in its report, it would like to present some further recommendations for the Ministers to consider.

RECOMMENDATION 22: The practice of progressively reducing the amount of LTC benefit or support paid whilst a claimant is in hospital should be reviewed as it seems unfair that the claimant should have to make up any balance owed to his/her care home for the period spent in hospital.

RECOMMENDATION 23: The LTC Scheme should cover short term costs incurred when a period of more intensive care is needed for a claimant living at home. This can arise if a final period of palliative care is needed to allow a patient to pass away in his or her own home.

RECOMMENDATION 24: The LTC Scheme should acknowledge that many claimants spend considerable amounts adapting their accommodation to meet their care needs e.g. fitting stair lifts, installing accessible washing facilities, purchasing adjustable beds. It is suggested that such capital expenditure should be regarded as part of relevant expenditure to reach the care costs cap.

RECOMMENDATION 25: The LTC Scheme should also acknowledge that claimants receiving live-in care in their own homes have additional expense in providing food, heat, power, transport and so on for their carer. It is suggested that an allowance should be made so that these expenses are regarded as part of relevant expenditure to reach the care costs cap.

12. Appendix 1: Professor Johnson Report

STATES OF JERSEY

Health & Social Security Scrutiny Panel

Long Term Care Review

PANEL ADVISER REPORT

Professor Malcolm Johnson

Introduction

As the implications of population ageing have slowly gained political attention across the developed world, where the over 85s are the fastest growing sector, there has been much concern about how to organise and resource the health, housing and care needs of older people. Long term Care Schemes have been developed in a number of countries (France, Australia, The Netherlands, Germany, Japan, among them). But for many the costs look too daunting, the issues of social equity too testing, the politics too difficult and the failure of the world of insurance to become active partners have made for continuing deliberation and repeated inability to decide. Not least among those who have continued to kick the ball into the long grass is the UK.

So the States of Jersey are to be congratulated on the foresight, political will and expertise that was brought to bear in the creation of the Long Term Care Scheme, which passed into legislation in 2013.

Changing patterns of illness in the younger disabled and the oldest old

Long term care is required by two distinct groups of people. A smaller group who from birth or later acquired disabilities needing considerable help across many domains of their lives. Health and social care are usually the largest component, but education, mobility and workplace provisions are also important. In these cases supporting family carers to enable the most normal lives achievable is critical and here the Social Security system is central as a partner with other government departments. In earlier times the life expectancy of many with severely disabling conditions was short. Even in the 1980s people with learning disabilities like Down's Syndrome, 88% would die by age 20 (Kucik et al, 2013). For those born with spina bifida survival rates were even less favourable. Life expectancy for people with Down's syndrome has increased dramatically in recent decades, to 60 today.

This group of younger disabled people is well represented by a range of voluntary agencies, a number of whom form the core of service providers. They are strong and vocal advocates of what people with disabilities on Jersey need and should be provided with. This was evidenced in The Review Panel's open Consultations. Well-presented papers containing their assessment of the new Scheme and its shortcomings were delivered in writing and followed up by attendance at the public hearings. Significantly, not many written representations were lodged on behalf of older citizens by individuals or organisations.

A much larger and continually growing group is made up of older people. For some the need for sustained care and support arises in late adulthood, before standard retirement. But the great majority now develop physical and mental health conditions that will eventually take their lives, in the late seventies, eighties and nineties. Some of these life threatening illnesses will result in death after a relatively short period of decline, but in recent years there has been an exponential growth in those whose lives come to an end slowly and in increasing discomfort, isolation and depression.

Aware that these marked changes are little understood, are poorly translated into care arrangements and have a signal influence on developing patterns of Long Term Care, I set out below, the character of the shifting demography of old age. This section is designed to set the Review of the Jersey Long Term Care Scheme in broader context.

In what follows the data used is drawn from England sources, mainly the latest analyses of Office of National Statistics data, carried out by Public Health England. These statistical agencies are routinely used as primary comparators by the States of Jersey statistical Office. Some references are made to the latest *Jersey Health Profile Data for 2013-2015* (2016).

Death in the Province of Old Age

The ageing of populations; where premature deaths are markedly reduced by better public health, control of infectious diseases, better housing, more nutritious diet, better medical care, more effective surgery and more efficacious medical care and pharmacy; has been well established for at least six decades. Demographers and gerontologists have been heralding the systematic extension of life expectation for the past six decades. Yet it has taken until the early years of the 21st century, for there to be operational recognition that we live in an ageing world which means more than having rather a lot of people we used to call pensioners. Slowly there has been a dawning understanding that living longer is an enormous benefit, which in turn means we have to re-think the whole of the lifespan.

Perhaps because the ramifications of the demographic revolution took so long to fully register in the collective mind and within the body politic, it should not be surprising that a significant artefact of this set of processes is that death has moved almost exclusively into old age, has also failed to properly register. The regular occurrence of what is inelegantly termed hospital 'elderly bed blockage' has arrested media and political attention. Yet this situation remains a source of profound healthcare anxiety.

The gain in life years has been remarkably consistent over a very long period. In a now classic paper Oeppen and Vaupel (2002) demonstrated that there has been an annual gain in expectation of life in northern Europe, of three months per year, consistently over the last 160 years. If the trend was coming to an end, the increments would show signs of tailing off. But the trend has so far remained as strong and consistent as ever. So regardless of any scientific breakthrough which might lead to further reduction in the causes of death, our collective age will continue to rise.

Premature deaths have also greatly reduced, to the point where 84% of deaths in England in 2013 were people aged 65 or older. 75% of all deaths were of people aged over 75, and 39% were 85 or older. All too many of those individuals (48%) end their lives, unsatisfactorily and at considerable public cost, in hospitals. A further 22% die at home, 25% in care homes and 6% in hospice care.

What older people die of is not, however, reflected in the statistics on causes of death across the UK population for all ages, which are generated and used to argue for the priority groups and the necessary forms of treatment and support that are required. A consequence of a disposition to see the predominant illnesses as the indicator of end of life care – and reflected in the origins of the hospice and palliative care movement – is a focus on cancer. Cancer has been a formative influence on thinking and practice, and the considerable charitable funds that flow to the cancer charities and hospices continue to have a disproportionately large voice. So too do major NHS programmes for the diagnosis and treatment of cancers.

In more recent times there has evolved a recognition that, despite the importance of cancers and a range of neurological conditions, they draw attention away from the dying experiences of a large swathe of older people. Those who die of other causes receive poorer medical care and

little or no palliative services. The patterns of illness among the very old present a different set of health and illness profiles.

Trajectories of dying

Lynn & Adamson (2003, 2008) in the US having analysed huge Medicare datasets, have concluded that "One useful way of envisioning care for elderly people who are sick enough to die, follows from classifying them into three groups; using the trajectory of decline over time that is characteristic of each major type of disease or disability. Each trajectory corresponds to a different rhythm and set of priorities in care.

Analyses of Medicare claims in the USA, show that about one fifth of those who die have a course consistent with the first group (mostly cancer patients); another fifth share the course of the second group (mostly organ system failure patients); and two-fifths follow the third course (frailty/dementia). The last one-fifth of those who die are largely those whose deaths are sudden. The three categories are depicted as: *Trajectory One: Short period of evident decline – typical of cancer*.

Most patients with malignancies maintain comfort and functioning for a substantial period. However, once the illness becomes overwhelming, the patient's status usually declines quite rapidly in the final weeks and days preceding death.

Trajectory Two: Long-term limitations with intermittent exacerbations and sudden dying – typical of organ system failure.

Patients in this category often live for a relatively long time and may have only minor limitations in everyday life. From time to time, some physiological stress overwhelms the body's reserves and leads to a worsening of serious symptoms. Patients survive a few such episodes but then die from a complication or exacerbation, often rather suddenly. For such patients, say Lynn and Adamson, 'on-going disease management, advance care planning, and [the provision of] services to the home are key to optimal care'.

Trajectory Three: Prolonged dwindling – typical of dementia, disabling stroke, and frailty.

Those who escape cancer and organ system failure are likely to die at older ages of either neurological failure (such as Alzheimer's or other dementia) or generalized frailty of multiple body systems. This large group of patients require supportive services at home, like meals on wheels, home help, regular nursing and then skilled palliative nursing. For many, care homes become the best option where round-the-clock care, every day, is standard and necessary.

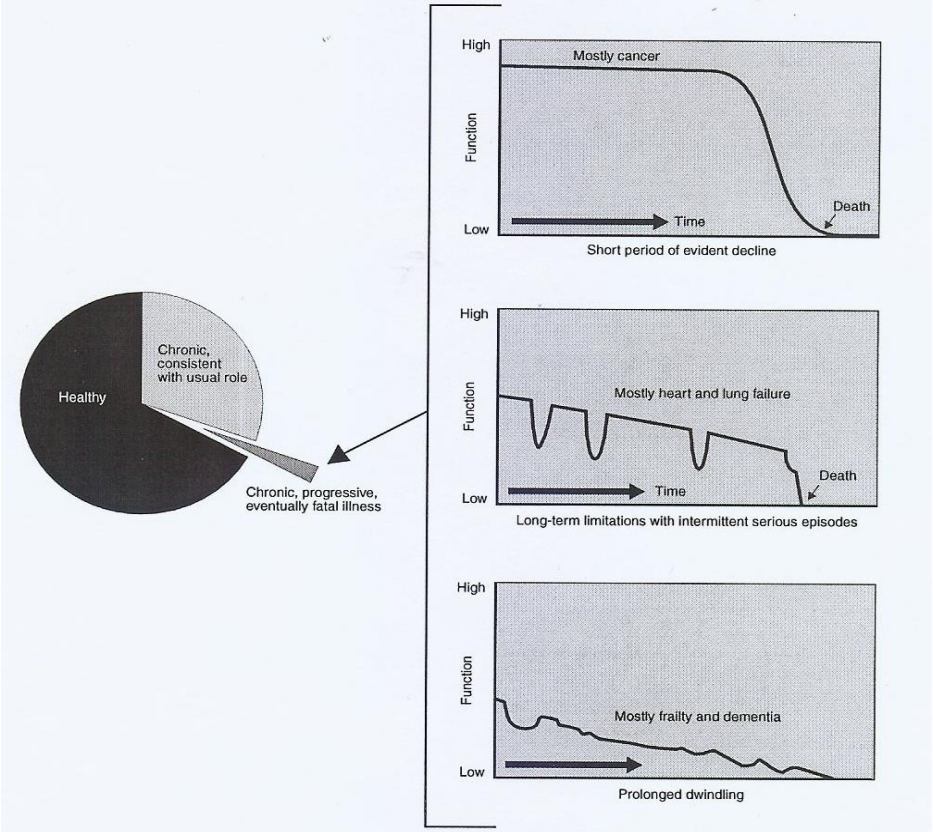


Figure 3. Chronic Illness in the Elderly Typically Follows Three Trajectories

The group that needs the greatest attention currently receives the least. Those whom Lynn and Adamson tellingly, but inelegantly, label as experiencing **'prolonged dwindling**' are the ones whose last lap is often painful and depressing for the individual and exhausting for their (often elderly) carers. It goes on for too long. Confined to the house, and with little to stimulate them, these older people deserve spiritual as well as functional care. This greatly disabled group are given detailed attention in Lynn et.al. (2008).

In a recent study of Care Homes in southern England, (Ennis et al, 2015) present their findings in a manner which reflects the dwindling trajectory and its growing presence. The study shows that out of thirty-eight nursing care homes which took part in the enquiry, (comprising 2444 individual residents) half of all residents fell into this category.

Living and dying with Dementia

In a detailed analysis of ONS 2014 data drawn from death certificates, the National Dementia Intelligence Network – in partnership with the Public Health England National End of Life Care Intelligence Network – has shown both the marked growth of dementia deaths and the shift in the places where people die (Khera-Butler, 2016). Significant among the findings are the dramatic changes in age standardisation rates where there is any mention of dementia, which have risen from 106 per 100,000 in 2001 to 188 per 100,000 in 2014. In parallel there are substantial changes in the place of death. From 2007, when 36% of all dementia deaths were in care homes, the proportion of people over age 65 who died with dementia in a care home had risen to 58%, whilst the proportion who died in hospitals has decreased (Khera-Butler, 2016).

"Alzheimer's disease and other dementias have replaced ischaemic heart disease as the leading cause of death in England and Wales for the first time. Last year, 61,686 (11.6%) out of a total of

529,655 deaths registered in England and Wales were attributable to dementia, according to the Office for National Statistics (ONS)."

That Dementia and Alzheimer Disease now the leading cause of death was reported in the media, but may not yet have registered in the collective mind; see:

BBC News http://www.bbc.co.uk/news/health-37972141

Daily Mail http://www.dailymail.co.uk/health/article-3934070/Dementia-leading-cause-death-people-living-longer-before.html

Returning to the *Jersey Health Profile Data for 2013-2015* (2016), there is an apparent mismatch with this international picture of increasing frailty and dementia. The following summary statements in the Report are concerning:

'*Cancers and heart disease remain the major causes of death locally as well as worldwide. The report shows that there are still premature deaths that are preventable, for example much liver and heart disease, many cancers, accidents and suicides.'*

'Mortality: The top 3 main causes of death in Jersey remain ischaemic heart disease, lung cancer and stroke. Cancers are the main cause of death locally. Cancers and circulatory disease account for more than 60per cent of all deaths. Over time there has been an increase in cancer deaths and a decrease in deaths from circulatory disease '

There is only oblique mention of dementia and no highlighting of it as a significant and growing cause of death, despite it topping the list in the UK.

It is possible that disease patterns on the Island differ significantly from those in England – or recording of the cause(s) of death on Death Certificates may differ.

A new report from Public Health England, *Place and cause of death for permanent and temporary residents in care homes,* (October 2017) reveals that '...taking into account those for whom dementia was the underlying cause of death (31%) and those for whom it was a contributory cause, the number who died with dementia can be estimated as high as 62%.' (p.7). It is inconceivable that these rates are not replicated on Jersey.

Long Term Care Schemes - The wider international debate

All developed societies have systems and arrangements which provide for the needs of older people as they become increasingly unable to live independently. Since the middle of the twentieth century the numbers who require a range of services and supported living have grown considerably. A trend which is expected to continue. So, governments have of necessity extended their traditional patterns of provision, only to find that they have become costly, fragmented and unfit for purpose. By the 1980s the pressures resulted in much discussion of the principles and models that might reflect the economic and political dispositions of diverse countries. In the following decade a variety of LTC Funding systems were introduced.

As reported by the World Health Organisation a decade ago (Muiser and Carrin, 2007),

"Separate schemes are found in both insurance- and tax-based systems. Austria, Germany, Israel, Japan and the Netherlands have adopted special laws to create a separate insurance

scheme for long-term care. In Denmark, long-term care is predominantly financed at the municipal level from local taxation. Slovakia is a middle income country that managed to integrate long-term care in the general benefit package, which is financed from insurance contributions, topped up with a substantial proportion of general taxation. In Lithuania, long-term care programmes are financed from municipal budgets." (p27)

The UK has made a number of attempts to find an LTC funding scheme, but at the time of writing, there is still no formalised proposal on the table. There was a Royal Commission on Long Term Care for the Elderly, 1997-1999, which failed to gain the support of all the Commissioners and was set aside in government policy. In short there was no consensus about what proportion of the costs of residential and nursing care should be met by the state and how much by individuals themselves. Successive attempts to introduce funding systems foundered on the same grounds; whilst the care system was expected to do more with reduced funding.

Continuing concern about the consequences of severe under funding led to respected independent analyses of the real costs, supported by the Joseph Rowntree Foundation (Laing, 2002). William Laing has continued to update his costing tool on a regular basis, up to the present day. It has been widely acknowledged as a valid calculator by commentators, but without response in government policy or practice.

An evaluation of funding systems in Japan, Germany, France, Australia and England, was carried out by Julien Forder and Jose-Luis Fernandez (2011), University of Kent. Its purpose was to inform the debate in the UK. In their paper they set out the key issues that need to be resolved before an LTC Scheme can gain public and political support:

- Whether the system is set up around an entitlement principle.
- The degree of risk pooling /insurance in the system.
- Clarity about the target population(s) e.g. elderly people or the whole population.
- The nature of the contributions that need to be made. Is it general taxation or hypothecated premiums.
- The extent that these funds are supplemented by charges or co-payments.
- The financial eligibility conditions.
- The scale of benefits.

The Dilnot Report

A further attempt to move to an acceptable formulation for England, set up by the Coalition Government, resulted in the *Report of the Commission on Funding of Care and Support: Fairer Care Funding* (2011). The report is better known as the Dilnot Report in recognition of the leading role of its Chair, Andrew (now Sir Andrew) Dilnot.

"The report highlighted that the current funding system is in urgent need of reform: it is hard to understand, often unfair and unsustainable. People are left exposed to potentially catastrophic care costs with no way to protect themselves.

Our recommendations set out how Government could dramatically improve the system and make it one we can be proud of. They include the following proposals:

- Individuals' lifetime contributions towards their social care costs – which are currently potentially unlimited – should be capped. After the cap is reached, individuals would be

eligible for full state support. This cap should be between £25,000 and £50,000. We consider that £35,000 is the most appropriate and fair figure

- The means-tested threshold, above which people are liable for their full care costs, should be increased from £23,250 to £100,000
- National eligibility criteria and portable assessments should be introduced to ensure greater consistency
- All those who enter adulthood with a care and support need should be eligible for free state support immediately rather than being subjected to a means test.

The Commission estimates that its proposals – based on a cap of £35,000 – would cost the State around £1.7billion"

http://webarchive.nationalarchives.gov.uk/20130221121534/http://www.dilnotcommission.dh.gov.uk/our-report/nd

The government could not countenance the key proposals, especially the £35,000 Cap, first proposing a cap of £72,000 and in the 2016 Conservative Manifesto raised the Cap to £100,000. The media branded this as a Death Tax and was swiftly abandoned. Since the election the issue has fallen out of policy sight, obscured by Brexit and the insecurities of a minority government.

In his October 2017 Royal London Lecture Andrew Dilnot pointed to the relatively low level of probability that older people will need extended periods in a care home and the potentially catastrophic cost long stays could involve:

"He (Sir Andrew) believes that costs should be seen in perspective. Around a quarter of today's 65 year olds will never need care but crucially, the vast majority of those who do, will only need it for some months at the end of their lives – leaving a median bill of about £20,000."

Architecture of the Jersey Long Term Care Scheme

Particular attention has been given to the Dilnot Report because it provides an authoritative and intelligible summary of the key principles that underlie the established systems from societies that operate in health and social welfare, like those of the UK including Jersey. It also offers a set of proposals and costings that are clearly present in the now operational Jersey Scheme and with some refinements in the LTC scheme.

An earlier States Review of the LTC Scheme (States of Jersey, 2013) prior to legislation, contained a comprehensive review of the literature and issues by Dr Susan Harkness, commissioned by the Panel. It remains a valuable source of reference, (Appendix 1, pages 18-46)) so no such detailed analysis is repeated here.

What does need to be said is that the Jersey Scheme was fashioned with the benefit of international thinking and practice. On the one hand it is more comprehensive and integrative than the Guernsey Scheme; bolder and more financially generous than successive UK governments have been willing to introduce. Moreover the projections of fiscal sustainability (not least from the Panel's actuarial and financial planning Advisors) appear to be sound.

Pooled risk

Critical to the Scheme's public acceptability, was the setting of the Care Costs Cap, at what is currently £54,480. Taking into account the higher cost of living on Jersey, this level just fits into the envelope of £25k to £50k that Dilnot recommended as socially just.

As a twin economic element, the Standard Co-payment, (the direct contribution all care home residents - except those on very low incomes- have to make, is set at £326.97 per week). This amounts to a rounded £17,000 a year, to meet the living costs that would apply if individuals still lived at home.

Respecting Jersey values and Jersey financial conventions. Inheritance

Jersey has long been proud of its identity as a welfare society, where healthcare (with the exception of some GP charges) is free at the point of need. Based upon a history of Parish care homes and local welfare the health and social care system is a citizen right. But citizen rights have always been mitigated by residence eligibility rules. In respect of the LTC Scheme, similar restrictions apply and eligibility is confined to adults who have lived in Jersey for ten continuous years. In the early years of the Scheme there are unlikely to be many who are excluded by residence disqualification, due to the relative youth of the sustained inward migration (currently at 1000 persons a year). As the Scheme matures, there will be a growing pressure to accommodate more migrant residents; especially as many of them will be contributors to the 1% (and rising) tax.

Low personal tax rates and the absence of inheritance tax are known features of the Jersey economy. With the assets disregard set at £419,000 and the existence of a Property Loan system at low interest rates, where house sale during the lifetime of the individual –even when in a care home- is not enforced, there is a balance of public sentiment and fiscal prudence that will have been important in endorsement of the Scheme. Nonetheless the housing shortage driving up property values and rental prices, there will inevitably be pressure on this arrangement.

Enhanced partnership working between Social Security and Health & Social Services

Even on a small island, the separate identity and working of government Departments has been as prominent and defended as anything to be seen in larger jurisdictions. So, it has been impressive to see and hear about the active collaboration of Social Security as the funding department and Health & Social Services as the operational arm of the Scheme. It was recognised in the planning stages and has translated into a continuing partnership, which is enabled through weekly meetings of senior officers.

Practical working of the Scheme

The Four levels - or is it six?

The original four categories of needs levels of payment have proved to be inadequate at the lower end and a fifth category is being introduced. Making such a refinement in response to the situations of beneficiaries demonstrates sensitivity and willingness to make adjustments. Yet

there is a downside to the addition of further complexity and increases in the number of thresholds. As the established profile of needs becomes clearer there may be benefit in re-calibrating in order to return to four categories.

Transfers from H&SS budgets for catastrophic illnesses.

It has long been the case that special and often costly arrangements have been made within a separate budgetary arrangement in H&SS. Some individuals through accidents or severe illnesses require intense care packages, expensive equipment or off-island expertise. This group of cases incurring 'catastrophic' costs have been excluded from the LTC Scheme (a sixth category). There may be important political reasons to maintain this set of provisions, but the matter needs to be kept under review.

Assessment scheme and issues

The Panel's own enquiries have revealed concerns amongst representatives of the younger persons with long term and life threatening conditions, but almost none from older people and their carers. It is increasingly clear that there are two separate schemes. One for younger people and another for those who are old and frail. Matters to be explored further.

We have been assured that the considerable backlog of assessments that built up in the first year of operation and beyond (at one stage over a hundred cases) has been reduced to almost nil.

THE FACE ASSESSMENT AND BUDGET TOOLS

Well founded and skilled assessment, leading to carefully crafted personal care plans, is central to the success of the LTC Scheme. The Department of Health & Social Services, following a procurement process, have worked intensively with the commercial company that has very recently changed its name to *Imosphere*, the creators and copyright holders of a suite of assessment tools, known as FACE.

From my two very intensive meetings on the assessment of individuals applying for LTC and the value and application of the suite of FACE assessment tools, I feel there are further questions to be asked about the validation of the tools – which experienced social worker assessors nonetheless found to be valuable and 'fairer' than the previous tools.

The CEO of what was then called FACE Recording & Measurement Systems, gave a vigorous and positive account of the tools his company have created to meet the requirements of Jersey's new systems and protocols. Senior representatives of H&SS spoke warmly in support and feel that the new assessment and budget tools bring greater reliability and consistency.

All assessments are carried out by professionals from social work, nursing and others. However training is only a one-off half day session. From the workshop slides that were provided, I could see how the self-assessments of clients were translated by the costings formula. However it was difficult to see where detailed assessments employing well validated measures, tested by practitioner use, were present in the system. For example, there was reference to Activities of Daily Living (ADLs) in the question form; but apart from the Waterlow scale, no other standard

measures appeared to be present. No Geriatric Depression Scale, no Mini Mental State, tests of propensity for falls, grip strength measures, balance, hydration, sleep, working memory, visual & hearing acuity and so on. Further documentation was promised and had it materialised, this may have assured me that the assessments were a good mix of personal self-assessments *and* independent measures.

Repeated internet searches to find copies of FACE Assessment tools failed to yield information – perhaps because of commercial copyright protection. But more disturbing, I could find no independent evaluations of the FACE tools. All the recognised assessment tools widely used in hospitals and care homes have been extensively tested and reported in peer-reviewed journals. To be able to find no such evaluation articles is concerning.

Service Integration and Departmental Collaboration

Having registered these concerns, I am nonetheless impressed by the integration of services across H&SS and the burgeoning partnership with Social Security.

Early review

The LTC Scheme has been in operation for a little over three years; having been formally introduced on July 1st 2014. The taxpayers ring fenced funding lodged in Social Security (based on the initial 0.5% contribution) was introduced on January 1st, 2015. In terms of the introduction of new and complex arrangements which involve government departments, service delivery professionals, third sector agencies, older and younger people in need of continuing support and their close kin, this has been a short time. People and systems need time to learn, adapt and refine what had previously been plans.

Some have expressed concern that the Review has been 'too early'. But the experience of working alongside the Panel over recent months has convinced me that the careful questioning by experienced politicians has served two very worthwhile purposes.

Firstly it has provided a public medium for those who have a demonstrable and continuing need for help and care, provided directly by The States or by other licenced bodies; to express concerns about the delays in assessment, the appropriateness of the 'the packages of care' arranged for them and their limited understanding of the Scheme. In the Panel's enquiries among their own constituents and Parish residents there was considerable evidence of confusion about how the new services would differ from the old and complaints of lack of comprehensible written explanations.

Secondly, the departments of government - principally Heath & Social Services and Social Security, plus Treasury & Resources – have been presented with carefully prepared questions about the way the Scheme operates. They have been required to answer both in writing and in Public Hearings. There have also been interviews conducted by the Panel's Advisers on technical matters. With a few minor exceptions, the responses from The States' employees at every level and from Ministers have been open, honest and remarkably constructive. Indeed we have witnessed an enthusiastic desire to make the LTC Scheme as good and as effective as possible.

What cannot be assessed at this stage is the longer term acceptability of the Scheme as it is inevitably amended to meet political requirements and the willingness of those who pay what, by any other name, is a tax and one that is scheduled to increase

Issues arising from the Review

Care Providers

There are continuing questions about the capacity of care providing agencies to deliver good care packages to those at home and for Care Homes to meet high standards. Also the reported increasing of weekly charges introduced by all providers since the Scheme became operational.

An important element in preparation for the LTC Scheme was the outsourcing and licencing of non-States commercial and third sector service delivery agencies. This process included the re-framing of contractual relationships with Family Nursing & Home Care and the range of other charitable organisations that provide residential and homecare services to younger people with disabilities.

A new market in care provision has been created which requires careful monitoring, both for the quality of its staff and services, but also for the charges made to individuals. As the new Independent Care Commission to reside in the Office of The Chief Minister comes into operation, the assurance of high standards and cost efficiency should be central to its role. With increasing difficulties in recruiting care staff and a particular problem in securing suitable trained nurses and social workers; the maintenance of a trained workforce will be a pressing problem.

Respite care

An important concern expressed by carers was the lack of well-defined provision for respite care. The Panel were clearly sympathetic to this oversight. The Health Minister in the Public Hearing undertook to address the matter.

Private insurance sector absence

Around the world where there are developed publicly provided health services, the insurance industry has been markedly absent in the realm of Long Term Care products. Their representatives argue that there is little appetite among younger people to invest in provision for their old age, when struggling to meet current living costs. Nonetheless it will be essential for the longer term sustainability of Schemes like the Jersey LTC, that those who can commit surplus income to the health and wellbeing of their future selves should be encouraged and enabled to do so. With insurance so eminently present in the island's financial sector, there must be opportunities to engage in discussions.

Demography of wealth

Wide disparities of earnings and wealth among the Jersey population are well known. In creating the LTC Scheme, an accommodation which 'pooled risk' to ensure the old, sick and disabled with small resources are provided with good care. Maintaining support for the Scheme over the longer term is critical to the welfare coalition of a diverse population. Weakening of the initial architecture would have a destabilising impact on an ageing society.

Mistaken notion that home care is always better and cheaper

It is a common error in public policy circles, to assume that care of people with health and social care needs, whether younger or older is both better and cheaper at home. Yet the presumption that 'living in your own home' is always preferable and better is an enduring fiction. Increasing evidence and awareness of loneliness and consequent high levels of depression among home based frail older people.

What we know about the living circumstances of these increasingly frail older people is that two thirds of those over 75 are women (more in the higher age groups as we saw earlier) and that two thirds of that group of women live alone; widowed or never married. As an overlay to the cluster of chronic illnesses that will bring their lives to an end they will typically suffer severe visual impairment. Of the 1 million 'blind' people in the UK, 90% are late onset sufferers, principally of the irremediable condition macular degeneration. Similar proportions are severely hard of hearing.

Dementia is essentially a condition of old age the incidence of which rises steeply with age and affects women more than men. Among the over 80s around 30% (Peters, 2001 in Stephan & Brayn) suffer from dementia. With or without a diagnosis of dementia, the Berlin Ageing Study shows there is a high probability that intelligence and cognitive functioning show decline during old age (Baltes, P., Staudinger & Lindberger, 1999

Depression is the epidemic condition of old age, although only 15-20% receive any treatment (Anderson and Krishnamoorty, 2012). It affects women twice as frequently as men and multiplies the impact of co-morbid conditions like angina, asthma, diabetes and dementia.

The prevalence of incontinence is less well documented but studies show (Chrome et al, 2001) levels of over one third of older people in the later stages of life. It increases with age and most rapidly in the eighth decade. As well as being distressing and uncomfortable, incontinence is frequently precipitated by other medical conditions, such as stroke and diabetes. (Harari, 2012)

As these debilitating conditions come in clusters, rather than on their own, they produce patterns of illness which make everyday life for the very old a struggle and a challenge for their carers. (Johnson, 2013). Together they leave many living in 'institutions of one', lonely and often isolated. Even 3 hours a day of paid care would be grossly inadequate. Yet at current hourly rates in Jersey –around £24 / hour- the cost would amount to £504 a week. Four hours a day (28 hours x £24) would be £588; which in turn is in the lower end of Care Level 3 and the cost of full time support in a residential home. Further consideration needs to be given to the best value and greatest benefit arguments of maintaining the dubious notion that living at home is always better.

Continuing lack of well-designed housing for older people

Well- designed specialist housing and supported living for older people in Jersey has long been a recognised but continuing issue. One important way of mitigating dependency levels (and therefore costs) and at the same time releasing family size housing, would be to increase the supply of specialist housing. Ideally it should be built close to local facilities and public transport

No references in LTC to new models of care and support.

There is still too little adoption of well-established forms of intergenerational living arrangements for older people. I recommend consideration of Homeshare; Shared Lives and Co-

housing as effective and cost effective ways of sustaining positive home living that avoids the isolation mentioned above.

CONCLUSIONS

- Jersey has taken a bold and very well-conceived step forward in creating its Long Term Care Scheme.
- As this commentary and the Review Panel's Report sets out, there have been early stage implementation problems related to delayed assessments and trained staff shortages; which may now have been corrected or are in the process of correction.
- The new outsourced 'care market' is at an embryonic stage and require very careful monitoring.
- As the Scheme moves into its second stage of operation it needs to take more account of the rising population of very frail – often combined with dementia - who are being somewhat overlooked.

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13. Appendix 2: BWCI Report

Independent Review of the Financial Aspects of the States of Jersey Long-Term Care Scheme

Prepared for

The States of Jersey Health and Social Security Scrutiny Panel

Prepared by

Michelle Galpin and Graydon Bennett

27 March 2018

Executive Summary

We have reviewed the financial aspects of the Long Term Care Scheme ("LTCS"), focusing on two key issues:

- How Jersey's ageing population is expected to impact on demand for the LTCS
- The financial sustainability of the LTCS

We would like to record our thanks to the Social Security Department ("SSD") and the Health and Social Services Department ("HSSD") for their assistance in providing information for our review.

Principal Findings

- There was an 18 month transitional period immediately after the introduction of the LTCS in order to allow the care needs of those in Group Homes to be assessed. Therefore the LTCS has only been fully operational for less than 2 years. Consequently it is quite early in the life of the LTCS and it may not have yet reached a stable state.
- The Long-Term Care General Information booklet is quite long and we found some parts difficult to understand. In addition, the information in the booklet about annual financial statements provided to claimants seems to be different from what happens in practice.
- Almost 1 in 4 of Jersey's population over the age of 85 have been assessed as having long-term care needs under the LTCS.
- The number of people in Jersey's population aged 85 and over is expected to increase from 2,150 to 4,750 over the next 20 years.
- The percentage of Jersey's population aged over 85 is expected to increase from 2% in 2015 to 4% by 2035.
- If the proportions of Jersey's population in care at each age remain broadly unchanged, the number of people assessed as having care needs is projected to increase from 1,200 currently to around 2,100 by 2035.
- The LTCS IT system is in the process of being updated.
- Data about the progression of individuals between care levels does not appear to be readily available from the SSD's current LTCS IT system.
- An actuarial review of the LTCS required under the Long-Term Care (Jersey) Law 2012 has not yet been carried out and appears to be overdue.
- We have not identified any concerns with the financial sustainability of the LTC Fund in the short-term, especially in light of the levers which the SSD Minister has available to control the payment outflows from the Fund.
- There is a risk that political considerations, in some circumstances, might make it difficult for a SSD Minister to be able to utilise all of the levers available to manage the financial sustainability of the LTCS in the longer-term.

Executive Summary

Recommendations

We recommend that the Panel considers:

1. Whether there are aspects of the LTCS which could be simplified for the benefit of both claimants and administrators.

2. If the process for communicating with claimants will be satisfactory once the new IT system is fully functional

3. Investigating whether the functionality of the new IT system will be able to record and report on:

    - The numbers of claimants in each care level at a given point in time;
    - How long a claimant spends in each care level; and
    - The progression of a claimant through the care levels

4. Whether statistics about the proportion of claimants in each care level and the transitions between care levels, can be recorded in such a way that they can be monitored easily by the SSD and published annually as part of the SSD Minister's annual report.

5. Proposing that a formal timeline be set for the first actuarial review of the LTCS. It would be helpful if the review could include an analysis of actual experience to date. This experience could then be used as the starting point for determining realistic assumptions for the future financial modelling of the LTCS.

6. Investigating whether information about the assets of those entering care can be recorded, so that any trends in the amount of these assets can be monitored, to refine the future financial modelling of the LTCS.

7. Recommending that any anticipated changes in care needs over time, as a result of medical advances in the treatment of diseases and conditions of the elderly, be factored into the model to project the LTCS's financial sustainability.

1. Introduction

1.1 Overview

BWCI Consulting Limited ("BWCI") has been engaged as an independent expert advisor by the Health and Social Services Scrutiny Panel of the States of Jersey ("the Panel"). We have been asked to assist them with some of the aspects of their review of the Long-Term Care Scheme ("LTCS").

1.2 Scope

The scope of our assistance is limited largely to items 3 and 6 of the Panel's Terms of Reference, as set out in Appendix A. Specifically, these items are:

3. To consider how the ageing population impacts on the Long-Term Care Scheme in terms of future demand.

6. To examine the financial health and sustainability of the ring-fenced Long-Term Care Fund including income received and expenditure incurred since the Scheme was introduced and projections of future income and expenditure.

We have also assisted with the drafting of some of the questions for the Panel hearings.

1.3 Data

We have been provided with copies of technical documents, publications and guides, transcripts and submissions to the Panel, regarding the operation of the LTCS. In addition, we have participated in discussions with the Panel's other expert adviser and key employees of the Social Security Department ("SSD") and the Health and Social Services Department ("HSSD") of the States of Jersey.

We have not carried out any independent verification of the data or information supplied to us and have relied on its accuracy; any data limitations identified during the cause of our review have been noted in the relevant section of the report. Details of the relevant information we have considered are provided in Appendix B.

We would like to record our thanks to the Social Security Department and the Health and Social Services Department for their assistance in providing information for our review.

1.4 Terminology

In this report, reference to the LTCS includes the rules to qualify for financial assistance, the level of benefits provided, and all procedures and structures currently in place for the effective operation of the LTCS.

The assets of the LTCS are invested in the Long-Term Care Fund ("LTC Fund") and are used to provide three different types of financial assistance:

- the universally available Long-Term Care Benefit ("LTC Benefit"),
- the means-tested Long-Term Care Support ("LTC Support"), and
- a loan secured against property, the Long-Term Care Property Loan ("LTC Property Loan").

1. Introduction (continued)

1.5 Structure of Report

We have summarised the main features and benefits of the LTCS in Section 2. In Section 3 we consider the implications of the ageing population. In Section 4 we consider the experience of the LTCS since its inception. In Section 5 we discuss the current modelling to project the future operation of the LTCS by the SSD. In Section 6 we consider the long-term sustainability of the LTCS and in Section 7 we highlight a number of risks which could affect the LTCS's financial sustainability and suggest strategies to manage or mitigate these risks.

1.6 Scope and Limitation of Advice and Compliance

The report has been prepared solely for the benefit of the Panel. Please see Appendix C for further details.

Any figures set out in this report have been determined for the purpose of our review. They may not be suitable for purposes other than those intended.

Our estimates have been made on the basis of the LTCS data provided to us as at 31 May 2017 (except as noted elsewhere in this report). Other specific limitations and caveats are contained elsewhere in this report. They all make up an integral part of the report.

Any user of this report should request an explanation or amplification of any matter on which there is any doubt.

Overview of LTCS

2.1 Overview

The establishment of the LTCS was agreed by the States in 2013, when it accepted the detailed proposals set out in document P.99/2013. The LTCS provides three different types of long-term care funding for Jersey residents who satisfy the qualifying criteria. These three types of funding, which are listed below, are described in more detail in later sections of this report:

- LTC Benefit
- LTC Support
- LTC Property Loan

Funding for the LTCS comes from a combination of States grants and contributions paid by Jersey residents who pay income tax. The current contribution rate is 1% of earnings up to the Upper Earnings Limit (£165,936 in 2017).

2.2 Coverage

The LTCS is designed to cover adults (i.e. those aged 18 and over) who have long-term high-level care needs. This includes people receiving care in their own homes ("domiciliary care"), as well as those in residential or nursing homes ("care homes").

2.3 Qualifying Criteria

The LTCS provides financial assistance to individuals who have lived in Jersey either:

- continuously for at least 10 years, as an adult, immediately prior to applying to the LTCS; or
- continually for at least 10 years, at any time as an adult, and also in the year prior to applying to the LTCS

There are also special arrangements for those needing care under the age of 28, since these individuals would not meet the 10 year adult residency criterion.

2.4 Care Needs

An applicant for financial assistance with long-term care costs is assessed by a healthcare professional in order to establish the extent to which they need permanent help with their daily activities. If their care needs are deemed to be sufficient, the person will be assigned to one of four care levels.

Care Level	Support Level	Example Needs
1	Moderate	Support with personal care morning and evening
2	High	Support needed throughout the day
3	Very High	Physical impairment preventing almost all independent activity
4	Extremely High	24 hour supervision

2. Overview of LTCS (continued)

2.5 LTCS Terminology

Information about the operation of the LTCS can be found on the States of Jersey website at https://www.gov.je/Benefits/LongTermCare/Pages/LongTermCareAbout.aspx.

This includes the LTCS General Information booklet, which is a useful source of information on the different aspects of the LTCS. However, at 28 pages, it is quite long. We found some aspects of the LTCS description complex to understand. We understand that the SSD is currently reviewing its explanatory literature and this would be a good opportunity to streamline the information provided in the booklet.

A glossary of the main terminology used in the LTCS General Information booklet is provided below.

Term	Description	Means-tested
LTC Benefit	Universal benefit covering standard care costs only and only after the LTC Cost Cap is reached	No
Co-Payment	The non-care related costs, such as food and accommodation	Yes Assistance through LTC Support or Income Support may be available
LTC Cost Cap	The limit on the standard care costs that a person has to accrue before the LTC Benefit is payable	N/A
LTC Support	Financial support with the non-care related costs and standard care costs before the LTC Cost Cap is reached	Yes
LTC Property Loan	Loan, secured against a property, to meet costs not covered by the LTC Benefit	No Not generally available if value of house is less than £394,000 or if other assets are more than £25,000

2.6 Initial Financial Modelling of the LTCS

During the developmental phase of the LTCS, with support from Oxera Consulting Limited ("Oxera"), the SSD carried out some initial modelling of the LTCS covering a 30 year time horizon to 2044. The modelling was used to compare the financial implications of different LTC scenarios. A "base case" set of assumptions indicated that the long-term contribution rate for the LTCS would need to increase to 2.9% by 2044. However, it was recognised that there is considerable uncertainty around this figure. In particular, the Oxera Report states:

"Given the uncertainty, the results of the model should not be considered accurate to several decimal places; rather, they give an indication of the overall trends and orders of magnitudes of key outputs, including the relative cost to the Fund of different policy options."

2. Overview of LTCS (continued)

The Oxera Report also illustrates the sensitivities of the LTC contribution rate to changes in some of the key assumptions. The results of the top 5 sensitivities are summarised in the table below.

Impact Ranking	Scenario	Impact on base case rate of 2.9% in 2044	Estimated Contribution Rate in 2044 %
1	Rate of real price effects (+2% increase in care costs, 1% increase in real wages)	+1.8	4.7
2	Initial care cost (+15%)	+0.7	3.6
3	Length of stay (+12 months)	+0.5	3.4
4	Population scenario (± net increase of 350 heads of household per year)	-0.3, +0.4	2.6 - 3.3
5	Domiciliary care population (± 150 in 2012)	-0.6,+0.3	2.3 - 3.2

This table illustrates that care cost inflation is expected to be a key driver in the determination of LTCS contribution rate increases. The Oxera modelling indicates that if care cost inflation were to be 2% pa above inflation and the median length of stay were to be 12 months longer than the median stay in the base case, then the LTC contribution rate could potentially exceed 5%. However, there are several "levers" within the LTCS structure which are available to limit the contribution increases. The use of these levers is discussed in Section 6.

We have provided further comments on the Oxera model in Appendix E.

2.7 Costs covered by the LTCS

A person needing care will either live in a care home or remain at home and receive domiciliary care.

Each of the four care levels within the LTCS is assigned a standard weekly care cost, determined from time to time by the SSD Minister. These standard care costs rise with increasing care levels. In addition to care costs, a co-payment is payable by those who are living in care homes. The co-payment represents the cost of providing food and accommodation (but not care) within a care home environment; it is independent of the level of care needs. If a person is receiving domiciliary care they do not have a co-payment, since they will already be meeting their daily living expenses in their own homes.

2. Overview of LTCS (continued)

The current standard rates are set out in the table below:

Care Level	Standard Weekly Care Cost	Standard Weekly Co-Payment (Care Homes Only)	Standard Weekly Gross Payment/Benefit (Care Home Only)
1	£369.18	£326.97	£696.15
2	£563.50	£326.97	£890.47
3	£814.52	£326.97	£1,141.49
4	£1,024.10	£326.97	£1,351.07

2.7.1 LTC Benefit

If a person has been assessed as having long-term care needs, and they satisfy the qualifying criteria (see Section 2.3), they would be able to claim the LTC Benefit. It is payable to everyone, but not until their assessed care costs have reached the LTC Cost Cap. The amount of the LTC Benefit payable will depend on a person's level of care needs.

The LTC Benefit does not cover any of the non-care related costs incurred when living in a care home. However, LTC Support may be available to help with these other costs if the claimant is unable to meet the full cost from their income or capital assets.

2.7.2 LTC Support

If a person has assets below a certain level ("the asset disregard limit"[107]), they can claim LTC Support to help with care costs before the LTC Benefit becomes payable. LTC Support is also available to help with the cost of the minimum co-payment. If a person claims LTC Support they are required to use their weekly income towards meeting the co-payment and their standard care costs.

2.8 Top-up Costs

Some care homes charge more than the standard rates. Any excess above the standard rate in the table in Section 2.7 would need to be met from the claimant's personal resources by the payment of top-up fees.

A person in care may also opt to pay top-up fees in order to secure a superior room or additional facilities. The LTCS does not meet the cost of any top-up fees directly. However, it may be possible to use a LTC Property Loan to cover top-up fees. This is considered in Section 2.10.

2.9 LTC Cost Cap

The LTC Cost Cap is the maximum amount a claimant would be required to pay towards their standard long-term care costs before the LTCS Benefit becomes payable. The cap is reviewed annually and currently stands at £54,480. A person accrues care costs at the standard rate towards the LTC Cost Cap, regardless of whether their actual care costs are more or less than this. In particular, if a person is receiving the majority of their care as unpaid care at home, perhaps from a partner or family member,

[107] The current asset disregard level is £419,000 and is broken down into £394,000 of property and £25,000 of other assets.

they are still deemed to be accruing care costs towards the LTC Cost Cap from the date they apply to the LTCS.

The LTC Cost Cap for two claimants who are married, or in a long-term partnership, is set at 150% of the LTC Cost Cap for a single person (currently £81,720). We understand that a claimant in this situation may apply either the LTC Cost Cap for a couple or a single person, whichever is achieved first. If both partners are in care, this option will persist for the surviving partner after one partner passes away.

Once a claimant has accrued notional costs in excess of the LTC Cost Cap, the LTC Benefit will cover their standard care costs for the remainder of their time in care. The time until the LTC Cost Cap is reached will depend on the length of time they have spent at each care level.

The table below shows the number of weeks a claimant would have to spend in a single care level before the LTC Cost Cap is reached.

Care Level	Standard Weekly Care Cost	Number of Weeks Until Care Cap Reached
1	£369.18	148
2	£563.50	97
3	£814.52	67
4	£1,024.10	53

For example, if a claimant was initially assessed as needing care at Level 1, and then 26 weeks later their needs had increased to Level 3, they would have accrued £9,598.68 (£369.18 x 26) of standard care costs at the point they were reassessed as Level 3.

They would then need to accrue a further £44,881.32 at Level 3 (or above) before being eligible for the LTC Benefit. If the claimant remained at Level 3 this would take a further 55 weeks (£44,881.32 ÷ £814.52) for a total of 81 weeks.

If instead, after 20 weeks at Level 3, the claimant was reassessed as needing care at Level 4, then they would need to spend a further 28 weeks at Level 4 before the LTC Benefit would be payable $\left[\frac{44{,}881.32 - (20 \times 814.52)}{1{,}024.10}\right]$.

According to the LTCS General Information booklet, the SSD records an individual's accrual of standard care costs and provides them with an annual statement. However we understand that, in practice, annual statements are not currently provided to claimants. We understand that the SSD is planning to review and amend existing literature to remove references to annual statements.

We understand that claimants are provided with a statement when they first apply to the LTCS, indicating the length of time until they are expected to reach the LTC Cost Cap. A revised statement would then be issued whenever the claimant's circumstances change (e.g. if their care needs change) and also when the claimant reaches the LTC Cost Cap.

We recommend that the Panel considers if the process for communicating with claimants is satisfactory.

2.10 LTC Property Loan

The LTCS recognises that in some cases a person will have substantial assets tied up in their property, but may only have limited income or insufficient liquid assets from which to pay their care costs before they reach the LTC Cost Cap, or to pay any co-payment. The LTC Property Loan addresses this.

2. Overview of LTCS (continued)

In certain circumstances, where the claimant (or their partner) owns a property with a market value in excess of £394,000 and their other assets do not exceed £25,000, they may be able to apply for a LTC Property Loan.

The precise criteria for eligibility for a loan and what it may be used for are quite complex. We have summarised the key features below. The LTC Property Loan is available to cover:

- Standard care costs when the claimant has not yet reached the LTC Cost Cap,
- Co-payment costs
- Additional top-up fees where the claimant's actual weekly co-payment is greater than the standard co-payment.

Interest on the loan accrues at 0.5% pa above the Bank of England base rate.

The LTC Property Loan must be repaid when the property next changes hands, i.e. at the earlier of the property's sale or inheritance.

We have been advised that claimants or their representatives are given information at the time of taking out a property loan. This is understood to cover how the arrangement operates: the amount being borrowed and how the interest is calculated. We also understand that the claimant is advised to take independent financial advice before signing the loan agreement. Currently statements with details of the amount owed are only provided on request, since they cannot be generated automatically by the SSD. We understand that the automation of annual statements is scheduled to be included in the second phase of the implementation of the new LTC IT system in 2018. This is discussed further in section 2.12.

2.11 LTCS Funding

The assets of the LTCS are ring-fenced. The financial arrangements are structured so that the contributions paid in by individuals, together with the grant from the Treasury[108] should broadly cover the cost of the financial support provided by the LTC Fund each year. A reserve is also maintained in the LTC Fund to meet short-term operational needs. Further details are provided in Section 5.3.

2.11.1 Contributions

Contributions are collected from those Jersey residents who pay income tax, including pensioners with sufficient income. While the headline contribution rate is currently 1%, in practice, the contribution is calculated in a similar manner to income tax, taking into account any income tax deductions, allowances, and tax reliefs. Consequently the effective rate paid will be less than the headline rate for most residents. The maximum contribution is capped, since it is based on income up to the Social Security Upper Earnings Limit (currently £165,936 pa). An example of the calculation is provided in Appendix D.

Contributions were originally expected to be collected from 1 January 2014 at a rate of 1.0%. However, following consideration of the conclusions of an economic impact assessment, undertaken prior to the launch of the LTCS, commencement of the collection of contributions was deferred by a year to 1 January 2015. Moreover, contributions were initially only collected at a lower rate of 0.5%. They were subsequently increased to 1.0% from 1 January 2016. As of the date of this report, the contribution rate remains at 1.0%.

[108] The grants from the SSD and HSSD are now paid directly by the Treasury as agreed in the MTFP.

2. Overview of LTCS (continued)

At the Panel hearing in September 2017 the SSD Minister indicated that the contribution rate is under review and could possibly be increased to 1.5% with effect from 1 January 2020. However, we understand that no formal decision has been made at this stage.

2.12 New IT System

The SSD is in the process of upgrading its LTC IT administration system. However, as of the date of writing this report, not all of the reporting tools were fully functional. Therefore we have not been able to review the new system's data reporting capabilities. The SSD have advised us that the first phase of the introduction of the new system was fully operational by the end of November 2017.

The data provided by the SSD for this review was extracted from the previous LTC IT administration system. As a result, there may be some discrepancies between the figures quoted in our report and those which may be generated by the new system in future. However, we do not have any reason to suspect that any differences would be material.

We recommend that the Panel considers investigating whether the functionality of the new IT system will be able to record and report on:

- The numbers of claimants in each care level at a given point in time;
- How long a claimant spends in each care level; and
- The progression of a claimant through the care levels.

We also recommend that the Panel considers whether the financial information provided to claimants will be fit for purpose once the new reporting tools in the LTCS IT system are fully functional.

2.13 Complexity of the Long-Term Care Scheme

The structural complexity of the LTCS, particularly the interaction of the benefit payments, support payments, care cost cap and asset disregard level limits, is not easy to understand.

In our view the degree of complexity is of some concern, particularly if claimants do not have the assistance of financially literate family members or friends to support them when:

1. Making the decision to apply for financial assistance under the LTCS,
2. Completing the application process and financial disclosures required to access the LTCS, and
3. Undergoing the assessment process to determine the level of their care needs.

We recommend that the Panel consider whether there are aspects of the LTCS which could be simplified for the benefit of both claimants and administrators.

2.14 Length of Experience

The LTCS has only been paying benefits for just over three years, since July 2014. During the first 18 months of this period transitional measures were in place. This transitional period allowed time for Group Home residents' care needs to be assessed and allocated to one of the four care levels. As a result, the LTCS has only been fully operational in the post-transitional state since January 2016.

Limited experience is therefore available for us to assess whether the LTCS has reached a stable state in relation to the proportions of claimants in each care level. Neither is there sufficient data available yet to determine how long claimants are expected to remain in a particular care level or the pattern of progression between care levels. This data will be important when considering what assumptions are most appropriate in any future modelling of projected costs.

2. Overview of LTCS (continued)

We recommend that the Panel considers whether statistics about the proportion of claimants in each care level and the transitions between levels should be monitored and published annually, as part of the SSD Minister's annual report. Some information was published in the 2015 report, but does not appear to have been included in the 2016 report.

2.15 Actuarial Reviews of the LTCS

Article 12 of the Long-Term Care (Jersey) Law 2012 ("the Law") requires the SSD Minister to appoint an actuary to review the operation of the Law. The actuary is required to report to the SSD Minister on both the financial condition of the LTC Fund and the adequacy of the contribution being paid into the LTC Fund. The actuary's report has to be laid before the States.

We understand that P.99/2013 envisaged that an actuarial review would *"be carried out every three years to examine the long-term viability of the LTC Fund and to guide decisions regarding the ongoing level of LTC contributions to be levied and the range of LTC benefits and support to be provided."*

The Law requires these reviews to be carried out every three years, starting from the 31 December of the year following the commencement of the relevant article (12 December 2013). P. 99 states that the first review was due as at 31 December 2016. In practice, it is unlikely that there would have been sufficient meaningful data available at that time to carry out a review and therefore it would not have been useful or cost-effective to do so. We understand that at the date of writing this report, no actuarial review of the LTCS has been commissioned.

We understand that the SSD Minister intends to commission an actuarial review in 2018 which will be made available to the States by the end of 2018. We recommend that the Panel considers proposing that a formal timeline be set for the first actuarial review of the LTCS. It would be helpful if the review could include an analysis of actual experience to date. This experience could then be used as the starting point for determining realistic assumptions for the future financial modelling of the LTCS.

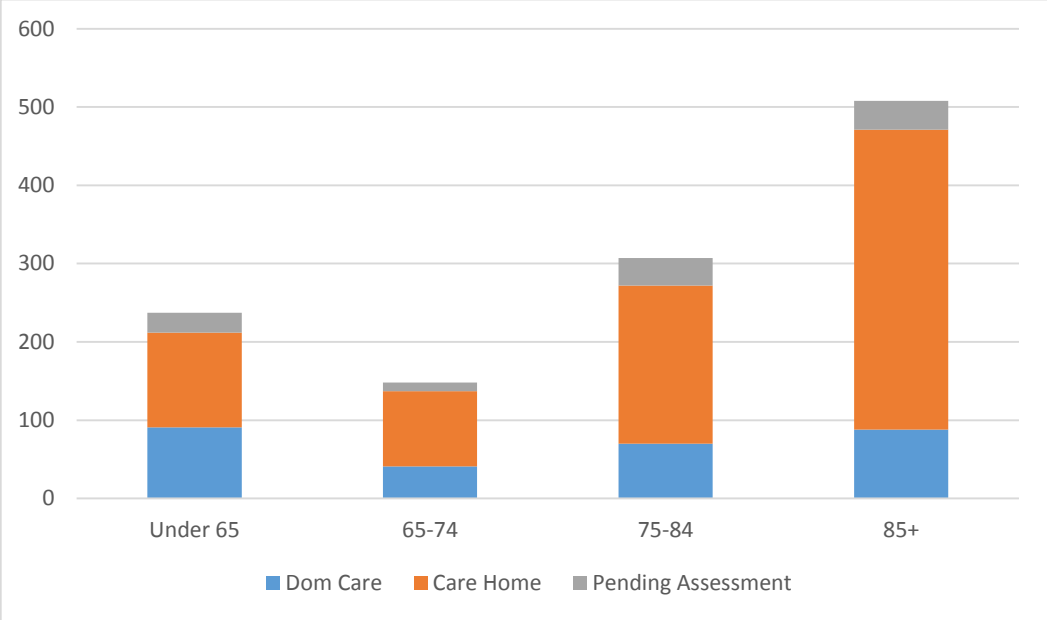
2.16 LTCS Projections

While the Oxera model was used to help the SSD to compare the costs of different LTCS structures before it was introduced, it is less appropriate for shorter-term projections of the expected cashflows into and out of the LTCS. Therefore the SSD has developed its own internal projection model. We consider the output from this model in more detail in Section 5 of this report.

3. Impact of Ageing Population

3.1 Impact of Ageing Population

The SSD provided us with summarised data of the ages of LTCS claimants as at 31 May 2017. This data showed that 80% of the 1,200 claimants at that date were aged over 65. The age distribution of the claimants is illustrated in the graph below. It shows that there is a correlation between age and long term care needs. As can be seen, the need for care is greatest amongst those aged 85 and above.



Based on estimated adult population data projected from 2015, the percentage of the adult population requiring care for these four age bands is illustrated below.

Age Cohort	Total Population in Cohort	Population in Care	Percentage of Cohort in Care
16-64	68,600	237	0.3%
65-74	9,020	148	1.6%
75-84	5,520	307	5.6%
85 and above	2,150	508	23.6%
Total	**85,290**	**1,200**	**1.4%**

The table illustrates how the number of people in the population with care needs increases significantly from around 1 in 20 in the "75-84" age group, to almost 1 in 4 for those aged "85 and over".

3.2 Population Forecasts

We have used the official population forecasts compiled by the States of Jersey Statistics Unit to consider the impact of Jersey's ageing population on the LTCS. These projections were derived from a baseline position as at 31 December 2015 using results of the 2011 census, updated for actual births, deaths, and migration levels over the period 2011 to 2015.

3. Impact of Ageing Population (continued)

While the numbers of births and deaths can be projected with a reasonable degree of certainty, the net inward migration figure is much more difficult to predict as it is affected by economic and political considerations.

Over the last few years Jersey has experienced very high rates of net inward migration; the average figure between 2013 and 2015 was 1,000 pa. The average falls to 900 pa if the ten year period from 2005 to 2015 is considered. The Statistics Unit has produced population projections on several future net inward migration scenarios, ranging from 325 to 2,000 pa.

3.3 Baseline Position

As at 31 December 2015 the ratio of the non-working age population to the working age population ("the dependency ratio") was 50%. This ratio will change over time if the proportion of people of working age changes relative to the total population. The higher the dependency ratio the fewer people of working age there are in the population to support those who are over pension age. Therefore an increasing dependency ratio is expected to increase financial pressures on the LTCS. This is considered in more detail in section 3.4.4.

Date (Scenario)	Working Age Population	Total Population	Dependency Ratio
31 December 2015 (Baseline)	68,600	102,700	50%

The definition of the working age population is currently 16-64, inclusive. By 2031 the pensionable age in Jersey will have increased to 67. The official projections for future changes in the dependency ratio do not take account of this change explicitly. The Statistics Unit has estimated that the increase in pensionable age would reduce the dependency ratio by 6 percentage points from 2031 onwards. However, for consistency with the official published statistics, we have not reflected this refinement in our figures.

The dependency ratio projections do not take account of any future potential social trends or policy changes as the population ages, which might encourage individuals to delay or phase retirement beyond pensionable age. This means that, in practice, the actual dependency ratio could be lower than projected. However, it is unlikely that social or policy changes will mitigate the increase in the dependency ratio entirely.

3.4 +700 Net Migration Scenario

The SSD model used for short-term projections of the LTCS (see Section 2.16) assumes that net inward migration to Jersey each year will be 700 individuals ("+700 scenario") over the 5 year projection period. Birth rates and death rates are estimated, based on observed trends in Jersey and are largely independent of the level of net migration.

3.4.1 Forecast Increase in Dependency Ratio

The table below shows the forecast working age population, total population, and dependency ratios under the +700 scenario at the end of 2025 and 2035. The dependency ratio is forecast to increase by 6 percentage points by 2025 and by a further nine percentage points by 2035.

3. Impact of Ageing Population (continued)

Date (Scenario)	Working Age Population	Total Population	Dependency Ratio
31 December 2015 (Baseline)	68,600	102,700	50%
31 December 2025 (+700 scenario)	71,900	112,500	56%
31 December 2035 (+700 scenario)	74,000	121,800	65%

3.4.2 Forecast Increase in Population Aged 85+

The following table shows the breakdown of the forecast population by age band. The increase in the proportion of the population over age 65 clearly demonstrates that Jersey's population is ageing; by the end of 2035 nearly a quarter of the population is expected to be aged 65 or older. At the same time, the proportion of the population of working age is falling. As highlighted in section 3.1, the numbers in the population over age 85 will have the greatest impact on the numbers with care needs. The table shows that the percentage of the population aged 85 or more is expected to double by 2035. The actual number of people over the age of 85 is projected to increase from 2,150 currently to 4,750 in 2035.

Date (Scenario)	Proportion Aged 0-15	Proportion Aged 16-64	Proportion Aged 65-84	Proportion Aged 85+
31 December 2015 (Baseline)	17%	67%	14%	2%
31 December 2025 (+700 scenario)	17%	64%	16%	3%
31 December 2035 (+700 scenario)	16%	61%	19%	4%

3.4.3 Estimated future care population

Assuming that the current percentages of the population with care needs remains the same in future, we estimate that by 2025 the numbers with care needs would have increased from 1,200 to over 1,500. By 2035 this could increase to around 2,100. The calculation of these figures is illustrated below:

Age Cohort	Percentage of Cohort in care	2025 population	2035 population	Estimated numbers in care	
				2025	2035
16-64	0.3%	71,900	74,000	216	222
65-74	1.6%	11,410	14,130	183	226
75-84	5.6%	7,150	9,250	400	518
85 and above	23.6%	3,160	4,750	746	1,121
Total	-	**93,620**	**102,130**	**1,545**	**2,087**

3. Impact of Ageing Population (continued)

3.4.4 Financial Implications

As Jersey's population ages, it is expected that the financial demands on the LTCS will increase. This is because not only is the working age population projected to reduce as a proportion of the total population, but the proportion aged over 85 is also projected to increase. The former is expected to lead to lower taxable income and therefore contributions to the LTCS, while the latter is expected to increase the numbers with care needs and hence the payments out of the LTCS.

While the population projections do not include any information about expected income or assets, in our view it is reasonable to assume that the average income of the working age population will exceed the average income of the pensioner population. As a result, the per capita contribution to the LTC Fund across the total population of Jersey resident tax payers is expected to reduce over time, in real terms, if the current arrangements remain unchanged. As a result the contribution rate would be expected to increase over time, even if the number of long-term care claimants remained the same.

As well as an expected fall in contribution income, the LTC Fund is simultaneously expected to experience increasing demand for payments. In particular, as the proportion of the population over age 85 increases, so too will the number of claimants under the LTCS. Therefore the expected *per capita* outflow under LTC Benefit and LTC Support will also be expected to increase. The amount of financial assistance provided by the LTCS can be controlled, largely by the SSD Minister, using a range of financial "levers" (discussed in Section 6.1.)

3.5 Sensitivities

We have illustrated the effect on the dependency ratio and proportion of the population over age 85 under the +700 net migration scenario. However, the Statistics Unit has prepared projections using a range of different possible migration scenarios. These provide an indication of the volatility and sensitivity of the projection results, especially over longer projection periods.

As already highlighted, of greatest significance for the cost of the LTCS is the increase in the proportion of the population aged 85 and above. Since it will take many years for the migrants to reach the 85+ age band, the increase in the proportion of the population in this age bracket is largely independent of migration rates over the 20 year period being considered. While the current proportion of the Jersey's population over age 85 is 2%, this is set to double by 2035 under all net migration scenarios is considered in our review.

The table in section 3.5.1 includes the projection results at 31 December 2025 under three scenarios: +325 net migration, +700 net migration, and +1,500 net migration. The table in section 3.5.2 provides similar projection results ten years later as at 31 December 2035.

3.5.1 Forecast Position in 2025

Date (Scenario)	Working Age Population	Total Population	Dependency Ratio	Proportion Aged 85+
31 December 2025 (+325 scenario)	68,800	108,400	58%	3%
31 December 2025 (+700 scenario)	71,900	112,500	56%	3%
31 December 2025 (+1,500 scenario)	78,600	121,200	54%	3%

3. Impact of Ageing Population (continued)

3.5.2 Forecast Position in 2035

Date (Scenario)	Working Age Population	Total Population	Dependency Ratio	Proportion Aged 85+
31 December 2035 (+325 scenario)	67,400	113,100	68%	4%
31 December 2035 (+700 scenario)	74,000	121,800	65%	4%
31 December 2035 (+1,500 scenario)	87,900	140,400	60%	3%

Under each of the net migration scenarios considered above, the dependency ratio is forecast to increase from the 50% level as at 31 December 2015, implying a smaller working population and a larger population over age 65, with a higher associated proportion of the adult population likely to require long term care. The increase in the dependency ratio is smaller for higher assumed rates of net inward migration. However, prolonged periods of high levels of net migration are unlikely to be sustainable in the long term, due to infrastructure and resource constraints in Jersey. In the very long term, if migrants remain in Jersey after retirement they will increase the pensioner population and ultimately increase the numbers with care needs.

3.6 Asset Distribution

The contributions payable by an individual into the LTCS only depend on their taxable income. The contributions are independent of a person's assets.

While the LTC Benefit is available to all, regardless of their level of income or assets, the means-tested LTC Support is only available to those with both insufficient income and assets below the £419,000 disregard level. A LTC Property Loan is available to those with insufficient income to cover all of their costs, but generally only if they have a property worth over £394,000. This means that the demand for financial assistance from the LTCS will be affected by the interaction of changes in the demographic profile of Jersey's adult population with asset and income levels. While there are detailed population projections available, we have not been provided with any financial projections of income or assets for Jersey residents. We understand from discussions with the SSD that such information is not readily available.

The distinction between assets and income is important when assessing the financial stability of the LTCS. People with lower taxable incomes will pay less in contributions into the LTC Fund than those with higher incomes (see Appendix D). Older people who may receive a pension, rather than income from employment, will generally have lower taxable incomes and so will be expected to pay less, or no income tax.

Wealthier people with assets in excess of the asset disregard limit will typically only claim the LTC Benefit, while those with more limited assets may also claim LTC Support. This is because over time, once a claimant's assets have been exhausted, they may qualify for LTC Support.

A person's total long-term care costs could vary quite considerably, before they receive the LTC Benefit, depending on their care needs during that period. The total costs (standard care costs and standard co-payment) range between approximately £72,000 and £103,000 for a person in care.

3. Impact of Ageing Population (continued)

Therefore, while the LTC Benefit is payable after a certain level of care costs have been accrued, regardless of the level of care needs, a person with lower level care needs will potentially have spent significantly more on the co-payment than someone with higher care needs, before they receive the LTC Benefit.

3.7 Interaction of Income and Asset Levels

While there is a correlation between income and assets, is it possible for a person simultaneously to have a large amount of assets and very low income, or conversely high income and low assets, depending on their personal financial circumstances. The categories shown in the table below are not binary, but represent a spectrum through which a person may move over time.

	Lower Income	Higher Income
Lesser Assets	Paying little to no LTC contributions Receiving both LTC Benefit and LTC Support	Paying contributions to the LTC Fund Receiving LTC Benefit and possibly LTC Support
Greater Assets	Paying little to no LTC contributions Receiving only LTC Benefit	Paying contributions to the LTC Fund Receiving only LTC Benefit

It is expected that the financial circumstances of the average Jersey resident will change over time in terms of both assets and income. For example, the next generation of pensioners may be less well-off than the current generation. This is because they may not have owned property during the housing boom of the latter half of the twentieth century, and they may have lower incomes in retirement as they will not benefit as widely as the previous generation from defined benefit pension schemes.

3.8 Conclusions

The interaction of a changing demographic profile with changes in income and assets over time means that it is difficult to predict how the financial position of the LTCS will develop over the next 20 years. However, if it is generally assumed that the next generation of pensioners requiring care will have less assets than the current generation, there could be an increase in demand for LTC Support. We recommend that the Panel investigate whether information about the assets of those entering care can be recorded, so that any trends in the amount of these assets can be monitored. This information could be of assistance in any future modelling of the LTCS.

4. Experience of the Scheme (2013-2017)

4.1 Introduction

We have reviewed the financial experience of the LTC Fund from 1 July 2014 to 31 May 2017, using the information provided by the SSD. Our analysis shows that since inception, actual experience in the LTC Fund has differed from the assumptions underlying in the Oxera Model.

4.2 Funding

4.2.1 States Grants

A notable deviation from expectations was the pattern of funding payments from the SSD and HSSD. We understand that this is due to other financial requirements which have taken priority at a departmental level. However, by carrying forward underspends and spreading payments over the period 2013-2017, the total amount of initial funding provided by the States grants ultimately was no less than originally forecast. It is just the pattern of payments that has differed, with lower payments in the earlier years and higher payments later. The States grants in 2016 amounted to £34 million.

4.2.2 Contributions

The initial contribution rate from tax payers was set at 0.5% in 2015. This increased to 1% in 2016, resulting in around £18 million in contributions in 2016. The written response from the Treasury and Resources Department has indicated that:

- Around 45,800 taxpayers contribute to the LTCS
- Around 15% of the LTCS contributions are paid by those over age 65.

Therefore the average annual contribution per tax payer is just under £400. The vast majority of these contributions (approximately £15 million) are currently paid by those under age 65.

4.3 LTC Property Loans

The take-up rate of LTC Property Loans has been lower than the SSD had expected. This is thought to be due to claimants having more non-property assets than originally anticipated. It is thought that these assets are being used to fund long-term care costs up to the LTC Cost Cap and co-payments, rather than the use of LTC property loans.

The Jersey census does not collect information concerning the level of savings of households and therefore it is difficult to model with any accuracy the length of time until a claimant receiving LTC Benefit will reach the asset disregard limit and therefore be eligible to receive LTC Support in addition to LTC Benefit.

The lack of information on assets was highlighted as an issue in Section 3.6.

4. Experience of the Scheme (2013-2017) (continued)

4.4 Income and Expenditure

The SSD have provided us with historical income and expenditure information for the LTC Fund from its inception in 2013 to 31 December 2016. The details are summarised below.

£'000	2013	2014	2015	2016
Cash Balance at 1 Jan	**-**	**11,701**	**11,800**	**9,438**
States of Jersey Grant	11,701	18,155	27,981	34,321
Contributions from Residents	-	-	8,443	18,008
Total Income	**11,701**	**18,155**	**36,424**	**52,329**
LTC Benefit Paid	-	3,148	13,665	26,523
LTC Support Paid	-	13,751	22,328	15,751
Administration	-	1,174	1,030	1,255
Total Expenditure	**-**	**18,073**	**37,023**	**43,529**
Income less Expenditure	**11,701**	**82**	**(599)**	**8,800**
LTC Bond Movement	-	(162)	(496)	(165)
Working Capital Movement	-	179	(1,267)	(2,776)
Capital Expenditure	-	-	-	(72)
Cash Balance at 31 Dec	**11,701**	**11,800**	**9,438**	**15,225**

The income and expenditure figures from 2015 onwards, together with details of the SSD's current projections up until 2020, are illustrated in the chart in Section 5.3.

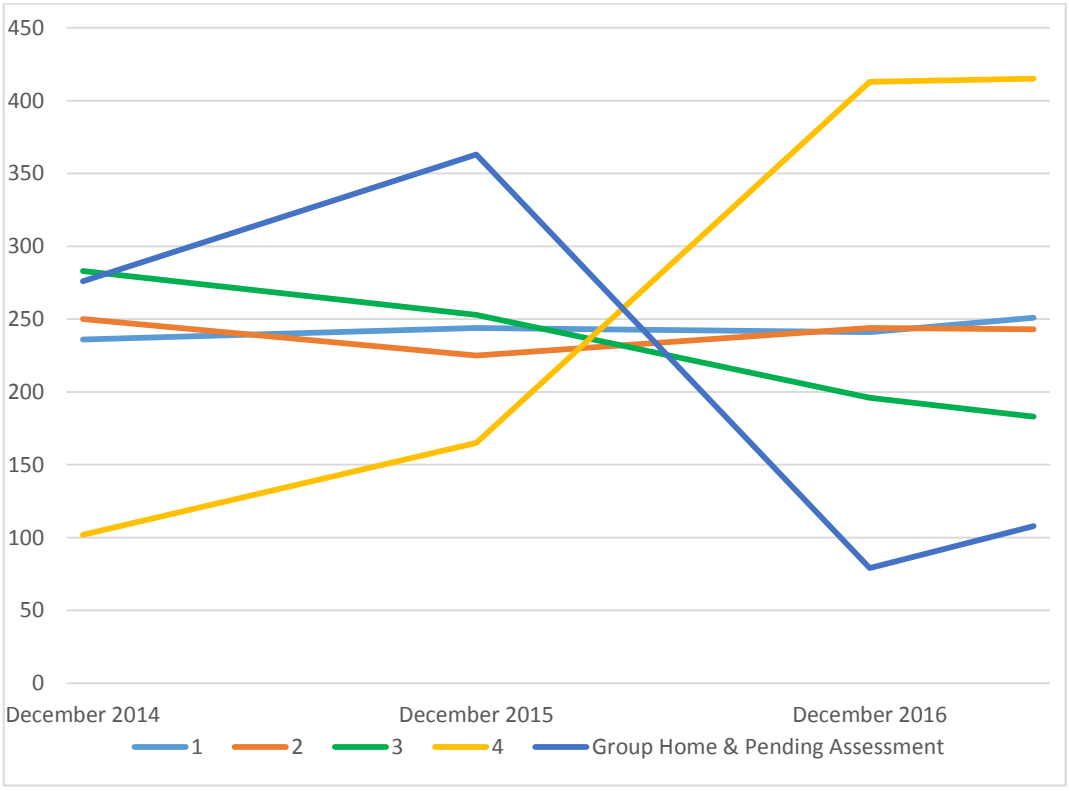
4. Experience of the Scheme (2013-2017) (continued)

4.5 Distribution of Claimants' Care Levels

The SSD have provided us with data regarding the number of claimants at each care level at the end of each year. It includes those currently in receipt of benefits, as well as those still accruing care costs towards the LTC Cost Cap. Due to the transitional period in the first 18 months, data from the first two years of the operation are not expected to be representative of the longer term patterns.

Date 'as at'	Care Level				Group Home	Total in LTCS	Pending Assessment	Total
	1	2	3	4				
31/12/14	236	250	283	102	120	**991**	156	**1,147**
31/12/15	244	225	253	165	80	**967**	283	**1,250**
31/12/16	241	244	196	413	N/A	**1,094**	79	**1,173**
31/05/17	251	243	183	415	N/A	**1,092**	108	**1,200**

The graph shows how the number assessed as needing a particular level of care has changed between December 2014 and May 2017.



The numbers in care levels 1 or 2 have remained fairly constant over the period. However, a notable change has been the sharp increase in the number of cases assessed as being at Level 4. This is in part due to the phasing out of the Group Home category transitional arrangements.

4. Experience of the Scheme (2013-2017) (continued)

In the first years of the LTCS there was a larger number of potential claimants awaiting assessment, including those in Group Homes. This backlog has reduced significantly as the LTCS has matured.

The number of people pending assessment includes those who have applied for financial assistance under the LTCS for the first time. It also includes those who have previously been assessed but, due to a change in circumstances, have been identified as requiring a reassessment.

The original Oxera modelling was based on the assumption that the numbers in care would be split evenly across the four care levels. The table below illustrates the actual percentages as at 31 May 2017.

Care Level	% of those in care
1	23
2	22
3	17
4	38

If it transpires that significantly more people than initially anticipated will be allocated to the highest care level in the longer-term, the projected cost of providing the LTC Benefit is likely to have been understated. However, in view of the limited time that the LTCS has been operating, it is not possible to determine if the position as at 31 May 2017 is expected to be representative of the LTCS in the longer-term. The long-term proportion in each care level will be a key assumption in any future projections for the LTCS. It is important that this is monitored so that assumptions about the patterns of care needs can be modelled as accurately as possible in future.

4.6 Transitions between care levels

It is noted that the first two recommendations in the Health, Social Security and Housing Scrutiny Panel's report of 6 November 2013 on the Long Term Care Scheme, were:

"1. Improved data on the average duration of long-term stay specific to Jersey should be gathered and maintained.

2. Regular analysis of Jersey-specific data relating to the duration of a long-term stay should be carried out in order to monitor and assess the cost implications of the long-term care fund and its financial condition. This should not only be included in the Department's actuarial review but also reported to the States on an annual basis."

It does not appear that these recommendations have been acted upon yet, since it was not possible for the SSD to provide us with any information regarding the average length of LTCS claims, the numbers transitioning between care levels each year or the number of deaths.

The SSD has informed us that of the claimants in care at the end of 2014, approximately 20% progressed to a higher level of care during 2015, and a further 16% progressed to a higher level of care over 2016.

5. Review of Financial Projections (2017-2021)

5.1 Background

The SSD uses their own in-house model to project the LTC Fund's anticipated annual income and expenditure over a five-year period. These projections are reviewed quarterly. The results are used to monitor the financial position of the LTC Fund and to assist the SSD when advising the SSD Minister on what potential changes may be required to the LTC contribution rate.

5.2 Methodology, Data and Assumptions

5.2.1 Methodology

The SSD's internal model uses an aggregate approach to modelling the financial position of the LTC Fund. Benefits are projected to increase in line with price inflation in Jersey and changes in the underlying population. The model does not reflect the benefits paid to each claimant individually. The results of the projections for the period 2017-2021 are summarised in section 5.3.

5.2.2 Population

In order to predict the number of potential claimants under the LTCS, the SSD model uses the projection of Jersey's population, assuming net inward migration of 700 people per year (see Section 3.4). Under this scenario, by the end of 2020, Jersey's population is projected to have reached 107,600. The working age population is projected to be 70,400 and the dependency ratio is expected to be 53%.

The contribution income is based on personal tax forecasts provided by the Treasury and therefore is not directly influenced by the net migration assumption.

5.2.3 Claims

Both the frequency and severity (i.e. initial care level) of future claims for LTCS Benefit and LTC Support are projected in the SSD model using actual observed claims data over the most recent quarter. The results are then applied to the projected population over age 85. As the LTCS matures and more experience emerges, future claims may differ from past experience.

We understand that the SSD model assumes that the distribution of the care population as at 31 December 2016 remains unchanged throughout the projection period. This does not necessarily imply that none of the claimants would progress through the various levels of care. Rather it assumes that the care population is stable, with every claimant exiting the system being replaced by another claimant moving up from a lower care level to a higher care level.

5.2.4 LTC Benefit

Increases in the LTC Benefit are effected via ministerial order to amend the Long-Term Care Services (Health and Social Services Charges) (Jersey) Law 2014.

We understand that the SSD Minister has agreed with care providers that the rates for the LTC Benefit will increase in both 2018 and 2019 by 1.5% pa; these increases have been incorporated into the SSD model. The model further assumes that inflationary increases to benefit rates beyond 2019 will be 3% pa.

There is also an allowance for a one-off increase in the LTC Benefit of 5% in 2018 in response to the expected additional costs associated with the introduction of the Regulation of Care Law. The Law comes into force from April 2018 and is expected to increase the costs of regulation across all care providers.

5. Review of Financial Projections (2017-2021) (continued)

5.2.5 Contribution Rates

The SSD Minister has stated in answers to written questions, that the intention is to leave the current LTCS contribution rate unchanged until at least the end of 2018. This is consistent with a commitment given by a previous SSD Minister.

The SSD model assumes that there will be no increase in the contribution rate until 2020. From 1 January 2020, the model assumes a contribution rate of 1.5%.

5.2.6 Investment Returns

The LTC Fund holds a portion of its assets in a cash account for short-term liquidity requirements. Any assets in excess of immediate cashflow requirements are held in the Common Investment Fund ("CIF"). This is invested in cash and highly liquid bonds, with the view of generating additional return. As at 31 December 2016, the asset allocation was 50% bonds and 50% cash.

The LTC Fund funding target is to maintain at least four months' worth of payments in reserve. We have been informed that approximately one month's worth of payments is kept in cash for operational needs, while approximately three months' worth of payments are invested in the CIF.

5.2.7 Administration Costs

The initial level of LTCS administration costs reflects the establishment work to design and implement the LTCS from its inception in 2014. The SSD model includes the cost reduction initiatives identified in the Medium Term Financial Plan ("MTFP").

5. Review of Financial Projections (2017-2021) (continued)

5.3 Projection Results

The SSD model has produced the following projections of income and expenditure over the five year period from 2017 to 2021.

£'000	2017	2018	2019	2020	2021
Cash Balance at 1 Jan.	**15,225**	**20,266**	**19,949**	**18,641**	**24,941**
States of Jersey Grant	31,795	28,706	28,879	29,832	30,816
Contributions from Residents	18,866	19,925	20,936	32,919	33,907
Investment Income	106	177	377	352	472
Total Income	**50,767**	**48,808**	**50,192**	**63,103**	**65,195**
LTC Benefit Paid	29,636	31,708	33,276	35,519	37,699
LTC Support Paid	14,268	15,444	16,438	17,793	19,120
Administration Expenses	1,351	1,466	1,340	1,340	1,384
Total Expenditure	**45,255**	**48,618**	**51,055**	**54,652**	**58,203**
Income less Expenditure	**5,512**	**190**	**(863)**	**8,451**	**6,992**
LTC Bond Movement	(297)	(260)	(224)	(209)	(197)
Working Capital Movement	(174)	(247)	(222)	(1,942)	(242)
Cash Balance at 31 Dec.	**20,266**	**19,949**	**18,641**	**24,941**	**31,494**
Cash Balance as a Proportion of Annual Benefit Payments	**46.2%**	**42.3%**	**37.5%**	**46.8%**	**55.4%**
Cash Balance as Months of Payments Remaining	**5.5 months**	**5.1 months**	**4.5 months**	**5.6 months**	**6.7 months**

The SSD's projections show that the LTCS is expected to have a surplus of income over expenditure in 2017 in excess of £5 million. However, due to the expected growth in the LTC Benefit and the LTC Support payments, income and expenditure are expected to be broadly in balance in 2018. By 2019 a shortfall of £863,000 is projected, based on a contribution rate of 1%.

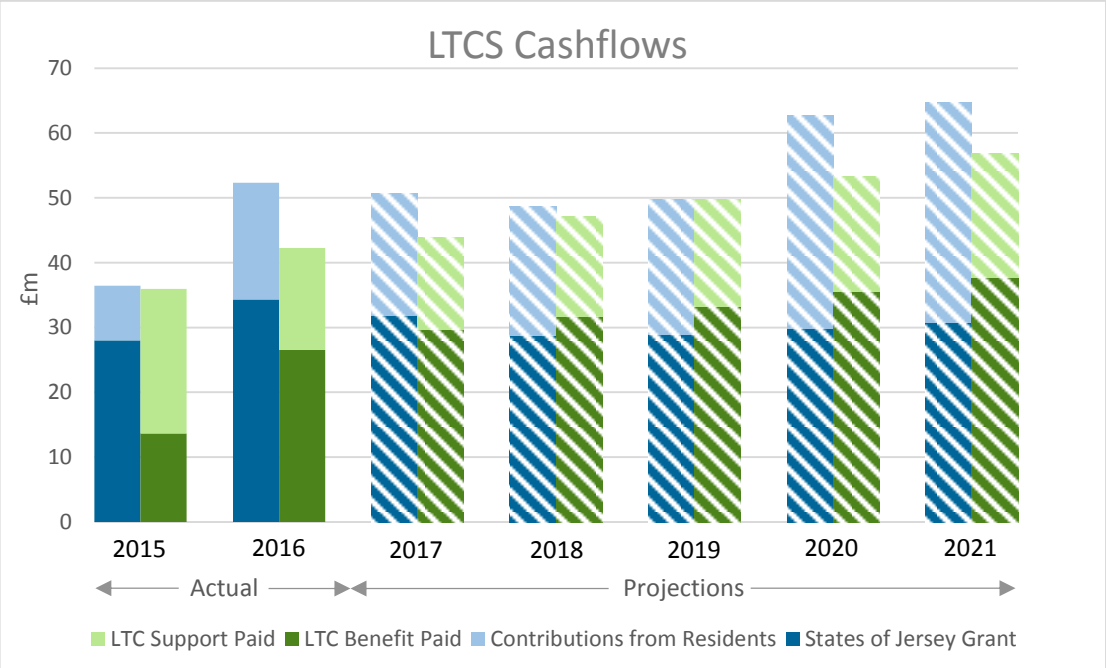
To avoid a larger shortfall in 2020, it is assumed that the contribution rate would increase to 1.5%. This would increase the expected contribution income substantially and restore the LTCS to an operating surplus. In 2020 Jersey tax payers are expected to pay almost £33 million into the LTCS. The States Grants would provide a further £30 million. In the same year the combined LTC Support and the LTC Benefits paid out are projected to be around £53 million.

We refer to this set of projections as the central projection.

5. Review of Financial Projections (2017-2021) (continued)

The actual income and expenditure in 2015 and 2016, together with the projected income and expenditure up to 2021 are illustrated in the following graph.

The green bars show the payments out of the LTCS; the blue bars show the expected income.



The chart illustrates how the payments (green bars) from the LTCS are expected to rise steadily, whereas the projected income (blue bars) is more variable. Contributions from tax payers are expected to need to increase from 2020 if the LTCS's income is not to fall below its expenditure. It also shows that LTC Benefits (dark green bars) are expected to become a larger proportion of the total payments out as the LTCS matures.

5.4 Sensitivity of Results

As we do not have a copy of the SSD's internal model, we requested that the SSD produce a number of sensitivity runs to show the impact of variations in the underlying assumptions. The two key rows corresponding to the light blue section in the table in Section 5.3 are repeated for each sensitivity run.

5.4.1 Population

Impact of a decrease in annual net migration to +350.

+350 net migration £'000	2017	2018	2019	2020	2021
Cash Balance at 31 Dec.	20,266	19,949	18,641	24,941	31,494
Cash Balance as a Proportion of Annual Benefit Payments	46.2%	42.3%	37.5%	46.8%	55.4%

The SSD has confirmed that these figures are intended to be the same as the +700 net migration figures.

5. Review of Financial Projections (2017-2021) (continued)

Increase in annual net migration to +1500.

+1500 net migration £'000	2017	2018	2019	2020	2021
Cash Balance at 31 Dec.	20,266	19,903	18,507	24,707	31,158
Cash Balance as a Proportion of Annual Benefit Payments	46.2%	42.2%	37.2%	46.3%	54.7%

It can be seen that variations in the level of net migration have little impact in the short term. This is because the majority of claimants are aged 75 or more, whereas most immigrants will be of working age. The impact of different population projections is expected to be greater in the longer term.

5.4.2 Claims

While it is not possible to vary the number of claimants receiving care at each of the four care levels, we have estimated that a 15% reduction in the number of claimants receiving care at levels 1 and 2, coupled with a 15% increase in the number of claimants receiving care at levels 3 and 4, would translate into an overall increase in expenditure in the LTC Fund of approximately 5%.

The projection shows that this would reduce the reserve in the LTCS by around £2 million by 2021, relative to the central projection.

+5% benefit payment £'000	2017	2018	2019	2020	2021
Cash Balance at 31 Dec.	20,266	19,526	17,733	23,475	29,393
Cash Balance as a Proportion of Annual Benefit Payments	46.3%	41.0%	35.3%	43.6%	51.2%

5.4.3 LTC Benefit

We have analysed the sensitivity of the LTC Fund to inflation by increasing the LTC Benefit by 1% each year over the projection period. We have also analysed the impact of lower inflation and the results are largely symmetrical, as expected, relative to the central projection.

+1% inflation £'000	2017	2018	2019	2020	2021
Cash Balance at 31 Dec	20,266	19,581	17,892	23,792	29,927
Cash Balance as a Proportion of Annual Benefit Payments	46.2%	41.2%	35.7%	44.3%	52.3%

5. Review of Financial Projections (2017-2021) (continued)

-1% inflation £'000	2017	2018	2019	2020	2021
Cash Balance at 31 Dec	20,266	20,317	19,388	26,089	33,061
Cash Balance as a Proportion of Annual Benefit Payments	46.2%	43.4%	39.3%	49.3%	58.6%

5.4.4 Contribution Rates

The model currently assumes an increase in the LTC contribution rate from 2020. As the model is expected to be very sensitive to this input, we have considered two alternative patterns for changes to contribution rates:

- Keep contributions flat at 1.0% for all years (no change from current rates)
- Apply a smaller increase to 1.25% in 2020

Flat Contributions at 1% £'000	2017	2018	2019	2020	2021
Cash Balance at 31 Dec.	20,266	19,949	18,641	13,968	9,218
Cash Balance as a Proportion of Annual Benefit Payments	46.2%	42.3%	37.5%	26.2%	16.2%

The above table shows that the cash balance in the LTCS would reduce rapidly from 2020 onwards if there were no increase in contributions. While not shown within the projection period, the LTC Fund would not be expected to be able to pay out the expected benefits from 2023 onwards if the contribution rate is maintained at 1%.

Contributions at 1.25% from 2019 £'000	2017	2018	2019	2020	2021
Cash Balance at 31 Dec.	20,266	19,949	23,875	24,688	25,590
Cash Balance as a Proportion of Annual Benefit Payments	46.2%	42.3%	48.0%	46.3%	45.0%

An increase in the contribution rate to 1.25% (rather than to 1.5%) from 2019 would increase the cash balance in the LTC Fund before beginning to decline more slowly than if the 1% level were maintained.

5.4.5 States Grant

We have also assessed the impact, relative to the central projection, of freezing the States grant in monetary terms by removing inflationary increases. This would reduce the value of the grants in real terms. We understand that the escalation of the States grant until 2019 is mandated by the MTFP and can only be altered by a change in the law. Therefore, the escalation has only been removed from 2020 onwards.

5. Review of Financial Projections (2017-2021) (continued)

Freezing States Grant £'000	2017	2018	2019	2020	2021
Cash Balance at 31 Dec.	20,266	19,949	18,641	23,988	28,604
Cash Balance as a Proportion of Annual Benefit Payments	46.2%	42.3%	37.5%	45.0%	50.3%

In the short-term the impact is small, relative to the central projection. However, over time the effect would be expected to be more significant and additional increases in the tax-payers' contribution rate would be required if the LTC Fund is to remain solvent.

6. Sustainability of the LTCS

6.1 Policy Levers

There are a number of "policy levers" built into the LTCS design, which the SSD Minister can utilise to adjust the inflows and outflows from the LTC Fund. The levers should enable the LTCS to be financially sustainable. Most of these levers can be exercised at the discretion of the SSD Minister, without approval from the States; important exceptions are changes to the rate of contributions collected from tax payers and the States grants. We comment on each of these levers in the rest of this section.

While these policy levers are available to the SSD Minister in theory, there may be political reasons why it would not be desirable to make use of them in some circumstances. However, a discussion of any political considerations falls outside the scope of our report.

The States of Jersey has approved a MTFP with a focus on controlling costs paid by the States. The MTFP may mandate targets for reductions in expenditure, and in certain cases, the MTFP may override scheduled increases in LTCS contributions or benefits.

6.2 Contribution Rate

The contribution rate is subject to periodic revision, since it was always envisaged that it would need to increase in the long term. Any change would need to be approved by the States. As illustrated in section 5.4.4, a small increase in the contribution rate can have a significant impact on the financial state of the LTCS.

6.3 States Grant

The States grant is scheduled to increase in line with inflation each year. Any changes to the grant (other than the inflationary increases) are expected to require a change in legislation or the MTFP. For example, a request could be made to the States to increase the grants above the rate of inflation, or for an ad-hoc top-up contribution in addition to the normal grant.

Conversely, the States could decide to freeze the level of the grant. This would reduce the States funding to the LTCS in real terms, which would be expected to place a financial strain on the LTCS in the longer term (see section 5.4.5).

6.4 Assessment Process

The HSSD carries out the assessment process and the determination of whether an individual meets the criteria for the different levels of care needs. In theory, more onerous thresholds or definitions of care needs could be set by the SSD Minister to influence the number of claimants accessing benefits.

6.5 Benefit Rates

The LTC Benefit rates could increase at less than the rate of inflation, or the benefit amount itself could potentially be frozen. However, this course of action is likely to be resisted by the long-term care providers and might impact on the level and quality of care available.

6.6 LTC Cost Cap

The SSD Minister has the power to vary the LTC Cost Cap. In particular, it could be increased it at a faster rate than the increase in the LTC Benefit. This would result in claimants having to fund a greater proportion of their care costs from their own income or assets, before receiving the LTC Benefit.

6. Sustainability of the LTCS (continued)

If this were to happen there could be an increase in claims for LTC Support for claimants whose income or assets were insufficient to fund the full cost of long-term care during the period before the LTC Cost Cap is reached. Therefore, it is likely that some of the potential savings from increasing the LTC Cost Cap could be offset by an increase in LTC Support payments.

6.7 Asset Disregard Level

The asset disregard level does not increase automatically with inflation each year. Indeed, it has remained at the same level since the inception of the LTCS.

The SSD Minister has the power to adjust the asset disregard level. The smaller the value of assets permitted to be retained by claimants in real terms, the more the cost burden falls on the claimant.

We understand that the asset disregard level is fixed for each claimant at the time of their application to the LTCS and that any subsequent changes to the asset disregard level would only apply to future claimants.

Of all the levers available, the asset disregarded is perhaps the simplest to use; keeping it at the same level in monetary terms would automatically reduce it in real terms and so increase the proportion of the overall costs borne by the claimant.

7. Discussion of Risks

7.1 Other Risks

As well as the financial risks to taxpayers around higher than anticipated increases in the LTC contribution rate, we have identified a number of other risks to which the LTC Fund may be exposed. Where relevant, we have also identified any risk mitigation or risk management strategies currently in place.

7.2 Liquidity Risk

In theory, the LTC Fund will receive income regularly throughout the year and pay out benefits at a more or less steady rate. In practice, however, there is a risk that the LTC Fund may be unable to make payments to care providers despite remaining in a surplus position. This could arise if the LTC Fund does not maintain a sufficiently large working cash balance (i.e. if assets are not easily convertible to cash or if does not receive sufficient cash inflows to match outflows).

Examples of liquidity risk include surplus funds which are invested in fixed income securities which cannot then be easily sold at an acceptable price when they are required. There could also be an accumulation of property loans which have accrued a large debt and have not yet been repaid.

We understand that the liquidity risk for investments in the CIF is managed by an asset allocation which retains 50% of assets in cash, and the remainder in a selection of highly liquid fixed income securities. Moreover, we understand that the LTC Fund aims to maintain a working cash balance equal to approximately 4 months of expenditure.

We also understand that the States grants and contributions from tax payers are paid into the LTC Fund on a monthly basis. Consequently there is a regular flow of cash entering the LTC Fund to meet immediate expenditures.

We have been advised by the SSD that the uptake of property loans has been slower than anticipated. In particular, there have only been 57 loans issued since the inception of the LTCS. At the time of writing this report, 37 property loans were outstanding. There is nevertheless a risk that if the uptake of property loans increases significantly, a large proportion of the assets of the LTC Fund could be held in illiquid property loans which will not be repaid until the property concerned changes ownership, either through sale or inheritance. Eventually, once the LTCS reaches a level of maturity and stability, it is expected that an equilibrium of sorts will be realised whereby old loans are repaid as new loans are created. We understand that the structure of the property loans puts the LTCS at a legally advantageous position to ensure repayment.

7.3 Inflation Risk

While the SSD Minister retains the power to change the LTC Benefit rates, inflationary pressures may increase operational costs for providers of long-term care at a greater rate than the SSD Minister feels able to increase the benefit rate.

7.4 Demographic Risk

In 2031 the pensionable age in Jersey is scheduled to increase to 67. This change is likely to alter working patterns gradually, by increasing working lives.

Other behavioural changes and lifestyle choices could also have an impact on the pattern of contributions made to the LTC Fund and the eventual demand for the LTC Benefit and LTC Support. People may choose to work beyond their pensionable age or to seek a phased retirement whereby

7. Discussion of Risks (continued)

working hours are gradually reduced over time until the employee ultimately retires completely. This could mean that their income remains higher for longer and so they may pay more income tax, thereby increasing the contributions paid to the LTCS.

The LTCS is also exposed to longevity risk in two ways. Firstly, there is the risk that LTCS claimants will live longer in the future due to advances in medical treatment and technologies. This could increase the time spent in long-term care and ultimately the demands on the LTC Fund. Secondly, if more people live to an older age they could be at greater risk of developing conditions or illnesses which require more intensive long-term care later in life. This could increase the demand for financial support from the LTCS.

7.5 Moral Hazard / Anti-Selection Risk

The introduction of a government subsidised scheme could have encouraged more applicants to claim. We have asked both the SSD and HSSD whether they have noted an increase in number of claimants resulting from the launch of the LTCS. However, no details have been provided to us.

7.6 Regulatory Risk

The introduction of the new Regulation of Care (Jersey) Law 2014 is expected to increase costs from 2018 onwards.

If the Jersey Ethical Care Charter or further regulatory changes were to be introduced then this might also increase costs.

Principal Findings and Recommendations

8.1 Impact of Ageing Population

8.1.1 Increase in Dependency Ratio

The analysis in Sections 3.3 to 3.5 shows that under each population projection scenario considered, the dependency ratio is forecast to increase steadily from 50%. This increase implies a smaller working age population relative to the retired population.

While the increase in pensionable age to 67, effective from 2031, will ameliorate the dependency ratio in that year, the increasing trend will continue thereafter if no other measures are implemented.

In the short term, the greater the rate of net inward migration, the slower the projected increases in the dependency ratio. However, a high rate of net migration over a prolonged period may not be sustainable as it would be expected to put increased demands on Jersey's infrastructure. We have not considered the potential repercussions of large inflows of immigrants further, as this falls outside the scope of this report. However, if immigrants were to remain in Jersey after pensionable age, they could increase the numbers with care needs.

8.1.2 Increase in Population over Age 85

There is a strong correlation between age and care needs, and the projected demographic change implies both lower contributions to the LTC Fund from taxpayers and greater care cost expenditure. Our review has identified that:

- Almost 1 in 4 of Jersey's population over the age of 85 have been assessed as having long-term care needs under the LTCS.
- The number of people in Jersey's population aged 85 and over is expected to increase from 2,150 to 4,750 the next 20 years.
- The percentage of Jersey's population aged over 85 is expected to increase from 2% in 2015 to 4% by 2035.
- If the proportions of Jersey's population with care needs at each age remain broadly unchanged from the current time, the number of people assessed as having care needs is projected to increase from 1,200 currently to around 2,100 by 2035.

8.1.3 Nature of Care Needs

Changes in the nature of care needs could also have implications for the financial stability of the LTC Fund. The length of time a claimant stays in care will be a function of the nature of their health issues. We understand that some physically debilitating conditions will generally require shorter stays in long term care than other conditions, such as dementia. We understand that evidence shows that dementia cases are increasing as a proportion of the conditions affecting older people.

8.2 Financial Sustainability

8.2.1 LTCS Levers

We have no concerns with the financial sustainability of the LTC Fund in the short-term, especially in light of the levers which the SSD Minister has available to control the outflow from the Fund. There is, however, uncertainty around whether a SSD Minister would be able to utilise all of the levers available fully in practice in the longer-term, due to political considerations.

8. Principal Findings and Recommendations (continued)

8.2.2 Future Modelling

It will be important that the LTC IT system is able to record and report on the data about how the care needs of those within the LTCS develop throughout the time that they are receiving care. Not only will this be required to provide claimants with information about the costs accruing towards the LTC Cost Cap and any LTC Property Loans, it will also be very important when considering what assumptions are likely to be most appropriate for the future financial modelling of the LTCS.

8.2.3 Actuarial Review

The first actuarial review off the LTCS has not yet been carried out. Subsequent reviews are required to be carried out at intervals of three years. The actuarial review process provides an opportunity to analyse the experience of the LTCS claimants to date and then use this information to refine the assumptions going forward. The review will also need to consider the pattern of future contributions to ensure that the LTCS is financially sustainable.

8.3 Recommendations

As Jersey's population continues to age and the demographic profile changes over time, the cost of the LTCS is expected to increase. While we do not have any concerns about the financial stability of the LTCS at this stage, our review has highlighted a number of potential areas where improvements could be made. These are reflected in our recommendations.

We recommend that the Panel considers:

1. Whether there are aspects of the LTCS which could be simplified for the benefit of both claimants and administrators.

2. If the process for communicating with claimants will be satisfactory once the new IT system is fully functional

3. Investigating whether the functionality of the new IT system will be able to record and report on:

    - The numbers of claimants in each care level at a given point in time,
    - How long a claimant spends in each care level
    - The progression of a claimant through the levels,

4. Whether statistics about the proportion of claimants in each care level and the transitions between levels, can be recorded in such a way that they can be monitored easily by the SSD and published annually as part of the SSD Minister's annual report.

5. Proposing that a formal timeline be set for the first actuarial review of the LTCS. It would be helpful if the review could include an analysis of actual experience to date. This experience could then be used as the starting point for determining realistic assumptions for the future financial modelling of the LTCS.

6. Investigating whether information about the assets of those entering care can be recorded, so that any trends in the amount of these assets can be monitored, to refine the future financial modelling of the LTCS.

7. Recommending that any anticipated changes in care needs over time, as a result of medical advances in the treatment of diseases and conditions of the elderly, be factored into the model to project the LTCS's financial sustainability.

8. Principal Findings and Recommendations (continued)

8.4 Conclusion

We hope that our review provides the information that the Panel requires in relation to their review of the financial aspects of their review of the LTCS. However, we would be pleased to provide any additional information required.

Appendix A Panel's Terms of Reference

1. To assess the current assistance for those registered on the Long- Term Care Scheme and (where applicable) their carers.
2. To determine whether the Long-Term Care Scheme meets the needs of those with long-term conditions including the assessment of need, the delivery of care and standards of care.
3. To consider how the ageing population impacts on the Long-Term Care Scheme in terms of future demand.
4. To examine eligibility for the Long Term Care Scheme with particular consideration of the 10 year residency requirements.
5. To examine existing resource and manpower provisions particularly in relation to:
    a. The assessment process
    b. Current waiting lists
    c. The transitional period of registering onto the Scheme
6. To examine the financial health and sustainability of the ring-fenced Long-Term Care fund including income received and expenditure incurred since the Scheme was introduced and projections of future income and expenditure.
7. To examining the methodology used for determining standard care costs, co-payments and the care posts cap, including the financial assessment process for receipt of long-term care support and property loans.
8. To consider the application of the Long-Term Care Scheme to particular groups with long term conditions, including:
    a. Young people upon reaching the age of 18
    b. Working age adults receiving care in their own homes
    c. Working age adults resident in a nursing or residential home
    d. Elderly persons receiving care in their own homes
    e. Elderly persons resident in a nursing or residential home
9. To consider measures that might be taken to improve public understanding and confidence in the Long-Term Care Scheme.

Appendix B Information Considered

This appendix sets out the documents that we have considered as part of the review.

- Long-Term Care – Briefing Note, Council of Ministers Report, dated 4 June 2013
- "Modelling the costs of a long-term care policy in Jersey", Oxera Consulting Ltd., dated 5 July 2013
- Long-Term Care Scheme: Report of the Healthy Social Security and Housing Scrutiny Panel (S.R.11/2013), presented to the States on 6 November 2013
- P.99/2013 "Long-Term Care Scheme" lodged 22 August 2014
- R.104/2016 "Minister's Report", Social Security Department, published 11 October 2016
- "Jersey Population Projections 2016 Release", States of Jersey Statistics Unit, October 2016
- Long-term Care (Jersey) Law 2012 (revised edition as at 1 January 2017)
- General Information leaflet "The Long-Term Care Scheme" dated March 2017 v5
- R&O.31/2017 "Long-Term Care Services (Health and Social Services Charges) (Amendment No. 3) (Jersey) Order 2017", dated 1 April 2017
- "LTC Fund Forecast" provided by SSD on 9 August 2017

And various emails, telephone conversations, meetings, transcripts, and written questions from the States of Jersey.

Appendix C Technical Details

This report is produced in accordance with the terms of the Client Agreement of 18 May 2017 between BWCI Consulting Limited and the States of Jersey Health and Social Security Scrutiny Panel on the understanding that it is solely for the benefit of the addressee.

It should be considered in its entirety as parts taken in isolation could be misleading.

Unless prior written consent has been given by BWCI Consulting Limited, this report should not be disclosed to or discussed with any third party other than those specified in the client agreement unless they have a statutory right to see it.

Notwithstanding such consent, BWCI Consulting Limited does not accept or assume any responsibility to anyone other than the addressee of this report.

Professional Standards

This report (and the work underlying this report) has been prepared in accordance with, and complies with all the applicable principles and provisions of the TAS 100: Principles for Technical Actuarial Work (version 1.0 effective from 1 July 2017).

Appendix D Long Term Care Scheme Contributions

This appendix provides an example of how the LTCS contribution rate would be calculated in the case of a single person.

2017 Rates and Allowances	
Standard tax rate	20%
Marginal tax rate	26%
Single Exemption Threshold	£14,550
Standard LTC Rate	1%
Marginal LTC Rate	1.3%
Upper Earnings Limit ("UEL")	£165,936

The income on which tax and the LTCS contributions is calculated is the lower of two figures. These are:

(1) Standard Rate method

(2) Marginal Relief method

The income figure is then capped by the UEL for the year.

For a person with income of £20,000 pa and no mortgage or dependent children their LTCS contributions under the two methods would be:

Standard Rate	Marginal Relief
1% of £20,000 = £200	1.3% of (£20,000 - £14,550) = 1.3% of £5,450 = £70.85

Therefore, in this case, the contribution would be £70.85.

The maximum contribution anyone would pay in 2017 would be 1% of £165,936 = £1,659.

Single Person's Income £ pa	LTC Contribution £ pa
20,000	7.85
40,000	330.85
60,000	590.85
80,000	800.00
100,000	1,000.00
150,000	1,500.00
200,000	1,659.00
250,000	1,659.00

Appendix E Review of Initial Financial Modelling (2013)

Background

Oxera Consulting Ltd ("Oxera") was engaged by the SSD to assist them to assess a range of policy options before the LTCS structure was finalised. Oxera modelled and analysed a "base case" scenario, together with a sensitivity analysis, to help the SSD consider the costs and funding options for the LTCS. Oxera's report for the SSD: "Modelling the costs of long-term care policy in Jersey" is dated 5 July 2013.The Oxera Model is complex and must currently be run from a dedicated computer. We refer to the data, assumptions and methodology adopted by Oxera for this modelling collectively as the "Oxera Model".

We have not been provided with a copy of the Oxera Model, nor does the scope of our report extend to an independent review of the Oxera Model. In particular, we have not analysed the results of the calculations of the Oxera Model.

The SSD have a working copy of the Oxera Model which could theoretically be used to investigate alternative structures or suites of assumptions. However, in practice, it may not be appropriate to do so, as we understand that the current operation of the LTCS differs, in some respects, from what was analysed in the Oxera Model.

Limitations of the Oxera Model

There are a number of inherent limitations in the Oxera Model, due to the assumptions that were made within the design of the model. These limitations were identified in the Oxera report, and these may have an impact on the results produced. Any model of a real world system will need to adopt simplifications and assumptions about reality in order to operate efficiently. The use of such simplifications and assumptions does not invalidate the model or the results it produces. The Oxera report discloses the following limitations:

- "When an individual enters the LTC system, they are assumed to need the same level of care until they exit the system."
- "The model assumes that the LTC Fund will meet the full cost of care for individuals under the age of 65 who require LTC."
- "Within the model, each agent is treated as an individual." In other words, the model does not differentiate between individuals and couples while, in practice, the LTC scheme applies different parameters to individuals and couples.

The Oxera report does not attempt to quantify the potential impact of these limitations on the results produced, although it does contain the results of sensitivity analyses performed on certain key assumptions.

We have also identified a number of other limitations within the Oxera Model but we are unable to quantify the impact of these simplifications on the model's results. In particular, we have noted that:

- When calculating contributions paid into the LTC Fund, the Oxera Model does not recognise contributions payable by pensioners. This may understate the contributions receivable by the LTC Fund.
- We understand that the Oxera Model assumes that all claimants will survive for two years from the date of entering care, regardless of their care level. We have not seen any analysis or experience to support this assumption.

The key assumptions used in the Oxera Model were provided by a number of States departments, including the SSD and the Statistics Unit. Assumptions with respect to length of stay in care were provided by a PSSRU (Personal Social Services Research Unit) analysis of BUPA data and adjusted to match the observed average length of stay in care in Jersey from a 2012 care home census.

Results

The Oxera Model generated a projected contribution schedule over a 30 year period from 2014 to 2044. In the base scenario, the contribution rate increased steadily over time from 0.2% to 2.9% in order to meet the costs of providing a long-term care to an ageing population.

Much has been made of the projected ultimate contribution rate of 3% in 2044 (rounded up from 2.9%) referenced in P.99/2013. It is generally accepted that LTCS contribution rates will need to increase over time as Jersey's population ages and advances in medical care permit those receiving long-term care to live longer. However, the projected long-term 3% contribution rate in 2044 should not be considered the definitive long-term cost of the LTCS.

The table below shows the expected contribution rates at 5 year intervals over the 30 year projection period. The current rate of 1% is higher than the base case projected rate in 2024. This would suggest that the LTCS may be more expensive than anticipated at the outset.

Year	Implied Contribution Rate to the LTC Fund
2014	0.2%
2019	0.5%
2024	0.9%
2029	1.3%
2034	1.8%
2039	2.2%
2044	2.9%

Sensitivities

The Oxera report identified a number of factors which could have a large impact on the contribution rates required in the future. The sensitivity of the model to the assumptions was measured by the impact on the implied contribution rate in 2044.

The range of results provided in the Oxera report suggests that the key sources of uncertainty in determining the contribution rate are inflation, initial care costs, and the size of the domiciliary care population.

14. Appendix 3

Panel Membership

Deputy Richard Renouf, Chairman

Deputy Geoff Southern, Vice-Chairman

Deputy Terry McDonald

Deputy Jackie Hilton

Senator Sarah Ferguson

Terms of Reference

1) To assess the current assistance for those registered on the Long-Term Care Scheme and (where applicable) their carers

2) To determine whether the Long-Term Care Scheme meets the needs of those with long-term conditions including the assessment of need, the delivery of care and standards of care

3) To consider how the aging population impacts on the Long-Term Care Scheme in terms of future demand

4) To examine eligibility for the Long-Term Care Scheme with particular consideration of the 10 year residency requirements

5) To examine existing resource and manpower provisions particularly in relation to:

    a) The assessment process
    b) Current waiting lists
    c) The transitional period of registering onto the Scheme

6) To examine the financial health and sustainability of the ring-fenced Long-Term Care fund including income received and expenditure incurred since the Scheme was introduced and projections of future income and expenditure

7) To examine the methodology used for determining standard care costs, co-payments and the care costs cap, including the financial assessment process for receipt of long-term care support and property loans

8) To consider the application of the Long-Term Care Scheme to particular groups with long term conditions, including:

    a) Young people upon reaching the age of 18
    b) Working age adults receiving care in their own homes
    c) Working age adults resident in a nursing or residential home
    d) Elderly persons receiving care in their own homes
    e) Elderly persons resident in a nursing or residential home

9) To consider measures that might be taken to improve public understanding and confidence in the Long-Term Care Scheme

Evidence Considered

Public and Private Hearings

30th May 2017

- Private Hearing with Witness 1
- Private Hearing with Witness 2

24th July 2017

- Public Hearing with Les Amis
    - Mr S. Findlay, Managing Director
    - Mr L. Norman, Chairman, Les Amis
- Public Hearing with Cheshire Homes
    - Mr D. Lord, General Manager
    - Mr J. Holey, Honorary Chairman, Cheshire Homes
- Public Hearing with Autism Jersey
    - Mr P. Sullivan, Chief Operations Officer

25th July 2017

- Public Hearing with Maison St Brelade
    - Ms M. Churchill, Finance Officer
    - Ms P. Thebault, Head of Home
- Public Hearing with Parish of St Helier Care Home representatives
    - Ms J. Garrod, Community Visitor for the Parish of St Helier
    - Mr N. MacDonald, Director of Finance for the Parish of St Helier

26th July 2017

- Public Hearing with Absolute Care
    - Ms A. Creighton, Owner and Director
    - Ms C. Moignard, Office Administrator
- Public Hearing with Total Living Care

  - Mrs J. Hopkins, Director
  - Mr C. Hopkins, Director

- Public Hearing with Enable Jersey

  - Mrs L. Bratch, Representative

18th September 2017

- Public Hearing with the Minister for Social Security

  - Deputy S. Pinel, Minister
  - Deputy G. Truscott, Assistant Minister
  - Mr I. Burns, Chief Officer
  - Mr A. Hacquoil, Finance and Governance Director
  - Mrs S. Duhamel, Policy Director
  - Mr S. Jackson, Operations Director

19th September 2017

- Public Hearing with the Minister for Health and Social Services

  - Senator A. Green, Minister
  - Mr M. Richardson, Assistant Director of Policy and Ministerial Support
  - Ms J. Poynter, Director of Operations for Community and Social Services
  - Mr P. Rendell, Acting Team Leader of the Adult Social Care Team