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Health and Social Security Scrutiny Panel



Respite Care for Adults

Presented to the States on 28th July 2015

S.R.4/2015

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1. EXECUTIVE SUMMARY

The terms short breaks or respite care are used to describe the time off that family carers and people with disabilities receive. These breaks can come in different forms including day centres, respite homes and outreach services. The Panel's review has assessed whether there is sufficient respite care provision for adults aged 18 – 65 in Jersey.

The need for sufficient respite care has been an issue for the States of Jersey to address for at least the last 10 years. Respite care is a vital service to carers as it helps keep families together and sustains carers in their long-term caring role. It is imperative that we recognise the extent of the carer's contribution to society as many offer lifelong support to their relative with 24 hour care. A carer's dedication reduces the pressure on the use of public funds and eliminates the cost of paying for staff to provide full-time care in residential settings.

Although the States of Jersey is having to make hard decisions on finding savings and making cuts to the public sector, additional expenditure now on respite services is likely to mean lower expenditure in the future on addressing the negative consequences of insufficient respite for carers.

The Panel has found that it is difficult to accurately assess the number of families who may need respite care because there is no cohesive information regarding the breadth and depth of disability in Jersey. The lack of statistical data may result in services not being tailored to meet people's needs and the inability to plan for future demand. The same issue was identified by the previous Panel during its review of respite care for children and young adults in 2012. The Panel has found no evidence to suggest that the situation has improved in this area and has recommended that a framework is developed by the end of 2015 to accurately record the numbers of people with disabilities.

The introduction of the Long-Term Care Scheme has meant that carers requiring respite care need to commission their own services. This principle of giving people more "buying power" may lead to inequalities of distribution due to a lack of understanding about how the system works.

The Long-Term Care Scheme may also lead to a greater reliance on outreach and inreach services. The Social Security Department has set respite care at 6 weeks annually but there may not be sufficient residential respite provision within the Health and Social Services Department to allow for this kind of demand. This may lead to families having no other choice but to access outreach and inreach services.

The Panel compared the number of residential beds within children's and adult services. It found that there are currently eleven respite beds in the children's service and five (which will decrease to four after July 2015) in adult services. Therefore, there is a danger that users of the children's service will have insufficient facilities for overnight residential based respite care when they reach 18 and enter into adult services. This could increase pressure on adult services in the future and may also lead to overreliance on outreach and inreach services.

The previous Panel highlighted significant issues with the transition process in 2012. It is disappointing that the process is still variable and families are still being left confused when their child reaches the age of 18. The Panel was told that in order to provide an effective transition service, two additional social worker posts are required. The Panel believe that securing these two

posts should not be solely relied upon in order to deliver an effective service. Action must be taken now to improve the service so that it is as seamless as possible for families.

Jersey only has one main day service for people with disabilities which is provided at the Le Geyt Centre. The Panel was told that the centre is no longer fit for purpose and does not have adequate facilities to meet the long-term needs of its service users. Plans have been developed for smaller bespoke premises to be provided around the Island with the main base at Le Geyt to become an autism centre. The Panel has found that more work needs to be done on this proposal and recommend that key decisions are formally recorded and published so that service users are able to track its progress.

The Panel was advised that there is a lack of appropriate transport for those most severely disabled accessing the day service who often spend a lot of time on the bus collecting other service users. The vehicle used is in its ninth year of service, although States of Jersey policy is that vehicles are not kept past seven years old. Disabled people deserve a better transport service and the Panel recommends that the Health and Social Services Department should investigate ways of providing a better service including working with the Voluntary and Community Sector.

The Panel found that there is and will continue to be a strong demand for overnight residential respite care in Jersey. There had been plans to develop a bespoke respite home for adults in 2013 and a lot of work was carried out by Andium Homes to develop the facility to be part of the final phase of the Le Squez housing estate. The Panel finds it unacceptable that no audit trail exists to explain the reasons why this was suddenly halted.

In order to address the lack of residential beds within the adult service the Health and Social Services Department plan to repurpose Maison Allo (currently a children's respite home) to provide respite care for people aged 14 – 21. The Panel is concerned that this is a quick-fix solution and will need to see firm evidence from the Minister that the proposals put forward will not reduce provision in the children's respite service. It is clear that had the bespoke adult respite home been progressed as planned, the current lack of respite provision within adult services could have been avoided.

Through talking with families it is obvious that respite care is clearly one of the most important services that a family can receive if they have an adult with a severe disability living in the home. Many carers face health and emotional problems due to the stress of being the primary support person. Therefore, it is important that the States of Jersey provide sufficient respite provision to allow carers a regular break from the considerable demands of providing constant care.

2. GLOSSARY

- **Short breaks/respice** – provision of short-term temporary relief by another agency to those caring for family members.
 - **Residential short breaks** are overnight stays in dedicated respite homes.
 - **Community short breaks** are day or overnight short-breaks in the community or in the person's own home (outreach/inreach).
- **Outreach and inreach** - these are domiciliary-style services which include taking people with complex needs either out into the community (outreach) or supporting them in their own home (inreach).
- **Day service** – attendance at a day centre or participation in activities away from home largely provided by Le Geyt Centre at Five Oaks.

3. KEY FINDINGS

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

1. There is no cohesive information regarding the breadth and depth of disability in Jersey. Information is held within different agencies including the Health and Social Services Department, primary care providers and the Social Security Department but there is a lack of concrete data. Understanding the breadth and depth of disability in Jersey is a key element to developing a strategy, without it, services will not be tailored to meet people's needs and there will be an inability to plan for future demand **[section 8.2]**.
2. There are eleven respite beds in the children's service and five (which will decrease to four after July 2015) within adult services. There is a danger that users of the children's service will have insufficient facilities for overnight respite care when they reach 18 and enter into adult services. The disparity between children's and adult services may increase pressure on adult services and lead to overreliance on outreach and inreach services **[section 8.3]**.
3. Three residential beds in adult services are required to meet the demand for short break services for wheelchair users. From the end of July 2015, when Cheshire Homes will no longer provide such a respite bed, there will only be one respite bed which caters for wheelchair users **[section 8.4]**.
4. Evidence suggests that the need and demand by wheelchair users for respite will increase rather than diminish with three more wheelchair users entering into adult services within the next three years. The Panel understands that there are several families waiting to access the wheelchair friendly room at Maurant Lodge. It is also noted that there are a number of students at Mont à L'Abbé School who need physical support or have other mobility difficulties, and therefore are likely to require ground floor residential respite facilities when they enter into adult services **[section 8.4]**.
5. There is currently no spare capacity to cater for emergency cases. If a service user was to go into crisis, other users may have reduced access to residential short break services **[section 8.4]**.
6. Some families and carers have been left confused about the Long-Term Care Scheme and what it would mean for them in terms of respite care. The principle of giving people more "buying power" may lead to inequalities of distribution due to a lack of understanding about how the system works **[section 9.4]**.
7. The Social Security Department has set respite care at six weeks for the year in relation to the Long-Term Care Scheme. However, there may not be sufficient overnight residential respite provision within Health and Social Services to allow for 6 weeks of respite care. This may lead to families having no other choice but to access outreach and inreach services **[section 9.4]**.
8. More services are available within the children's service compared to adult services. For example, one of the respite homes within the children's service has a hydrotherapy pool facility **[section 10.1]**.

9. No audit trail has been found of the decision to cancel plans for a new bespoke adult respite home. Evidence gathered during the review shows that there is and will continue to be a strong demand for this kind of respite care in Jersey **[section 10.1]**.
10. Home based respite services (outreach and inreach) have developed more readily in recent years whilst residential based respite services have contracted. The Panel believes that these types of respite services should be additional for families rather than a replacement for residential based respite **[section 10.2]**.
11. The previous Panel highlighted significant issues with the transition process in 2012. It appears that the process is still variable and families and carers are still being left confused when their child reaches the age of 18. The Panel has been told that in order to provide an effective transition service, two additional social worker posts are required **[section 10.3]**.
12. The Le Geyt Centre is no longer fit for purpose as a day centre and does not have adequate facilities to meet the long-term needs of the service users. Plans have been developed for smaller bespoke premises to be provided around the Island with the Le Geyt Centre building becoming an autism centre **[section 10.6]**.
13. The transport provision to take service users to and from Le Geyt Centre is not working properly. Many of those most severely disabled spend a lot of time on the bus collecting other service users. Financial constraints have meant that there are no funds to replace the current vehicle which is in its ninth year in service **[section 10.6]**.
14. The States of Jersey does not have any statutory obligations to fund respite care for adults. As a result, services could be an easy target for funding cuts, particularly in the current economic climate **[section 10.7]**.
15. The Health and Social Services Department has proposed repurposing Maison Allo, currently a respite home which sits within the children's service, to a young person's facility for ages 14 - 21. Not only might this disadvantage children aged under 14, it also fails to address the residential based respite needs for adults aged over 21 **[section 11.1]**.
16. The Health and Social Services Department plan to introduce eligibility criteria for those wanting to access adult respite services. Although eligibility criteria could ensure a transparent and consistent approach to allocating services, it should not mean that fewer families receive residential respite care as the Panel considers residential based respite care to be a crucial component in the service offered to families **[section 11.1]**.

4. RECOMMENDATIONS

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

The Minister for Health and Social Services should ensure the following –

1. By the end of 2015, a framework for collecting and collating data and monitoring and developing performance within both children and adult services should be developed. This should be developed using data obtained from the Disability Strategy and in accordance with an information management system which complements collecting information from other Departments **[section 8.2]**.
2. The Minister for Health and Social Services should ensure that overnight residential respite will continue to be provided to families and carers without having a negative impact on other services. In particular the Minister should ensure that wheelchair users have sufficient facilities which the Panel considers should have three accessible beds. The Department should work in partnership with organisations such as Les Amis who have offered to develop what is needed for families **[section 10.1]**.
3. The Panel was told that resources must be secured through the Medium Term Financial Plan 2016 – 2019 for two additional social worker posts if an efficient and effective transition service is to be provided. The Health and Social Services Department should develop new and innovative ways of working in order to provide an effective transition service within existing resources and not solely rely on securing funding for additional staff **[section 10.3]**.
4. By the end of 2015, the Health and Social Services Minister should publish an update on the Carers' Strategy 2013 - 2016. This should include what progress has been made since it was drafted in 2013 **[section 10.4]**.
5. The Chief Minister, through his Assistant Chief Minister, should engage more closely with the Service User Forum and use it as an opportunity to develop policy as it brings together people who have personal experience of multiple and complex problems. The Chief Minister's Department should publish formal records of the Service User Forum's meetings which include specific actions to be taken forward **[section 10.5]**.
6. The Minister for Health and Social Services should ensure plans for the future of the Le Geyt Centre are fully costed before June 2016 when the second part of the Medium Term Financial Plan 2016 – 2019 will be lodged. The Panel also recommend that key decisions regarding this development are formally recorded and published so that service users are able to track its progress **[section 10.6]**.
7. The Health and Social Services Department should investigate ways of providing a better transport service for users of day services including working with the Voluntary and Community Sector **[section 10.6]**.

8. The Minister for Health and Social Services should introduce a Social Services Law with regulations and guidance to accompany the law which include a requirement to provide a break for carers and for individuals with disabilities in order to improve the quality of their lives **[section 10.7]**.
9. A “Care Navigator” will be employed for a short period by the Health and Social Services Department to work with carers to identify unmet needs and choose the most appropriate respite to meet all of their needs. The Panel’s evidence suggests that support for carers in both the children’s and adult services is required and not just for a short period **[section 11.1]**.
10. In order to ensure repurposing Maison Allo is the right approach, the issues identified by the Special Needs Advisory Panel (SNAP) should be fully addressed and answered in writing before plans for the facility are implemented. This formal response to SNAP’s concerns should also be circulated to all service users of Maison Allo **[section 11.1]**.
11. The Health and Social Services Department should ensure that the eligibility criteria for accessing adult respite services are fair and consistent. Before finalising the criteria, the Health and Social Services Department should consult fully with the Special Needs Advisory Panel and other stakeholders **[section 11.1]**.

5. INTRODUCTION

5.1 Context and Background

Respite care or short breaks can be defined as the provision of short-term, temporary relief by another agency to those who are caring for family members. The term “short breaks” (or respite) is used to describe the time off that family carers and people with disabilities receive. These breaks come in different forms including day centres, respite homes and outreach services.

Respite is a service which is highly valued by carers of people with disabilities. Early intervention and regular breaks help to keep families together and sustain carers in their long-term caring role¹. Family carers play a crucial role in the development, health and well-being of people with learning disabilities. Many people with disabilities receive support from family carers and it is important that they have access to information, training and support. Many offer lifelong support to their relative, with 24 hour care. There is no precise data on numbers, but the UK has estimated that some 60% of adults with disabilities live with their families². It is therefore imperative that we recognise the extent of carers’ contribution.

It is important to consider the impact that providing care or support can have upon a carer’s health and well-being. Studies have demonstrated the positive effects on the well-being of families, and people with disabilities of short breaks³ (respite). The States of Jersey should value the carer’s role, as it reduces the pressure of using public funds. Unpaid carers will inevitably save money by eliminating the cost of paying for staff to provide full-time care in a residential setting.

The needs of those who access respite are often complex and varied. There is no one size fits all service. It is important to note that some people are born with special needs, whilst others can suddenly develop complex needs at any point in their lifetime through illness or injury. Therefore, some people need breaks in different ways, at different times and for different periods.

In 2012, the previous Panel conducted a review of respite care for children and young adults which identified a number of failings within the system. One of its main findings was that families caring for children with severe physical or mental disabilities have had to contend with a sometimes erratic and unpredictable respite service. Our review has aimed to assess whether there is sufficient respite care provision for adults (aged 18 – 65) in Jersey.

5.2 History

In 2005, the Jersey Association of Carers (JACI) requested that the States undertake a review of respite services for carers in Jersey. The findings of the review were based on a questionnaire and half day workshop with representatives from independent sector and statutory organisations with an interest or connection to carer’s issues. The review’s findings were that there was a lack of respite provision and that a more flexible and responsive range of respite services was needed. In addition to high quality residential respite there needed to be alternative provision including domiciliary, day and emergency respite⁴. This highlights that the need for sufficient respite care has been an issue for the States to address for at least 10 years.

¹ Renfrewshire Council Social Work Department. Review of Respite Services for Adults with Learning Disabilities, 2006

² Valuing People: A New Strategy for Learning Disabilities for the 21st Century. Department of Health, 2001

³ Health Needs Assessment Report: People with learning disabilities in Scotland, 2004

⁴ Ministerial Decision – MD-HSS-2007-0035 – Review of Respite for Carers

In 2008 it was identified that there was no adult short break service, either residential or outreach for people with complex needs. In a paper submitted to the Health and Social Services Minister of that time, it was noted that a residential based service to respond to people with more complex support needs was required. It also identified that outreach services for people on the autistic spectrum and a residential based service to respond to people with more complex and challenging behaviour was required. Funding was acquired in the Annual Business Plan 2009 to establish and fund additional short break services and resulted in an investment of £475k.

KPMG was commissioned by the Health and Social Services Department (“Health Department”) to review how services are provided and what steps will be required to ensure that Jersey can offer quality care. In 2011 KPMG published its report and identified that there were insufficient respite places, particularly for children and people with dementia. This increases the pressure on carers, and can cause individuals to be admitted to costly residential care more quickly⁵.

In 2011, Islanders were consulted on the future of Health and Social Services. Islanders recognised that failure to support carers could result in carers becoming patients themselves and also expressed strong views that more respite services were urgently required⁶.

P.82/2012 “Health and Social Services: A New Way Forward” was lodged in 2012 and outlined detailed plans for the future of health and social care services. This strategy was accepted by the States Assembly in 2012 and explained that improvements would be made to adult and older adult services in the community. This included promoting carer’s social inclusion particularly when there is a need for respite.

In recognition of these gaps in service, investment was made into dementia and children’s short breaks through non-recurrent funding from 2012, up to the point when P.82/2012 funding became available.

5.3 The Review

The Panel sought written and oral testimony from stakeholders and the public and held public hearings with the Ministers for Health and Social Services and Social Security. We are grateful to those who have contributed to our work and to the Ministers and their Departments for their assistance during our review.

The scope of the review has included respite provision for adults including; community short breaks often referred to as outreach services; residential short breaks and day services. Essentially, the Panel wanted to assess whether respite services for adults were fit for purpose and identify if there were any gaps or areas for improvement.

In this report the Panel begins by explaining the current provision of respite services in Jersey. We also consider the financial aspects of the service including the Medium Term Financial Plan and Long-Term Care Scheme. Taking into account the issues raised during our review, we consider what action may be required in order to improve respite services. The Health Department has already indicated changes within the makeup of both children and adult services which we have also considered.

⁵ P.82/2012 “Health and Social Services: A New Way Forward”, page 15

⁶ P.82/2012 “Health and Social Services: A New Way Forward”, page 33

6. ADULT RESPITE PROVISION

This section explains what respite provision is currently available for adults with disabilities. The Special Needs Service which is part of the Health Department provides social care and support for people in the community. People are able to access respite services through the Special Needs Service or being referred by a health professional such as a GP or health visitor⁷.

6.1 Residential based respite

Residential based respite services can provide a series of pre-planned short term placements. Respite care can be arranged on a one off or regular basis. It can be arranged for short periods of time (such as a few hours) or for longer stays. Respite care can usually be arranged on a planned basis, but emergency situations or waiting lists may impact on availability.

Les Amis is a Jersey based charity which has been in operation for 40 years. Their main objective is to offer care and support packages to children and adults with learning disabilities and/or associated conditions, through their residential, respite and outreach services. Adult respite care is provided at Mourant Lodge in Trinity and can cater for up to 4 adults on a daily basis. Mourant Lodge was built by Les Vaux Housing Trust and opened in April 2014. There is one room which provides for wheelchair users on the ground floor and three other bedrooms on the first floor⁸. The adult respite provision is also currently regulated.

Highlands Residential Care Home used to be the main provider of residential based respite and provided four respite beds which catered for wheelchair users. However, Highlands withdrew from the market in 2014 due to difficulties with sustaining the provision of short break services as its core business is residential and nursing care⁹.

When Highlands Residential Care Home did not renew their contract, Jersey Cheshire Homes agreed to a six month trial contract to provide one respite bed in order to meet part of the need. The Home was originally established to provide residential care to individuals over the age of 18 who are physically disabled and unable to live in their own homes.¹⁰ We understand that the Home will not be renewing its contract with the Health Department on 31st July 2015 due to a number of reasons which include:

1. The short-term nature of the stays (on average two nights) was not working well with residents and staff
2. The short-term nature was not utilising the Home's facilities
3. Staff were not able to build up a relationship with the users
4. The Home was never established to provide short-term respite care
5. There were concerns about responsibilities for ongoing wound care and reporting lines¹¹

⁷ Information sourced from States of Jersey gov.je website

⁸ Information sourced from Les Amis website at www.lesamis.org.je

⁹ Public Hearing with the Minister for Health and Social Services, 9th February 2015, page 21

¹⁰ Information sourced from Jersey Online Directory website at www.jod.je

¹¹ Email correspondence received from Jersey Cheshire Homes, 7th July 2015

6.2 Non-Residential based “respite”

Although these services are not respite services as such, they do contribute to giving carers a break.

The Le Geyt Centre is a day service which caters for people with profound and complex disabilities and also provides individual programs for people on the autistic spectrum. The service operates between 9:30 – 3:00pm and there are currently 61 users of this facility aged between 18 – 70.

Mont à L'Abbé School provides education for students with severe or profound and multiple learning difficulties aged 3 – 19, whose needs cannot be met within a mainstream school. The School supports the transition of students with learning difficulties to adult services including work experience, college placements and attending Les Amis and/or Le Geyt Services¹².

6.3 Group and Individual Homes

As well as providing respite care for adults and children, Les Amis also offer residential support to its clients in individual or group home settings. The St Saviour Service comprises of eight properties in several parishes. The properties, which range from a one-bedroom flat to five-to-six-bedroomed houses, are designed to provide residents, many of whom previously spent most of their lives in institutionalised care, with as normal a life as possible in ordinary residential areas in the community. Some live independently, with professional care support, or with Les Amis staff in situ 24/7.¹³ Currently Les Amis support 81 adults through this provision across the Island in 30 premises, of which 16 are regulated and the other 14 are inspected through the Approved Providers Framework.

Currently within the Special Needs Service, there are 3 group homes for people with physical and intellectual difficulties. The Panel was advised that the Community and Social Services residential strategy is to move people who use services to more personalised bespoke environments. To enable this to happen, the Department is working alongside Andium Homes and Jersey Property Holdings. Phase 1 is complete where 11 individuals now live in their own environments supported by staff from within the Learning Disability Service¹⁴.

6.4 Outreach and Inreach Services

In 2014, the States of Jersey established an approved provider framework (APF) to set standards of provision covering care at home to people over 18¹⁵. The APF has resulted in the following providers being able to offer outreach services:

- Les Amis
- Autism Jersey
- Tutela
- Family Nursing and Home Care
- All Care Jersey
- New Horizon's Support Services
- Christies Care (live-in provider)

¹² Information sources from Mont à L'Abbé School website www.montalabbe.sch.je

¹³ Information sourced from Les Amis website at www.lesamis.org.je

¹⁴ Information sourced from Social Work Team, email correspondence 11th March 2015

¹⁵ Information sourced from gov.je website at www.gov.je

- Able Community Care (live-in provider)

Outreach and inreach services provide short, flexible breaks to carers of adults with disabilities either in peoples own homes or in the community. Through an assessment conducted by the Social Work Team carers are allocated a fixed number of hours per week and are then free to choose when they would like to use those hours.

7. EMPLOYMENT OPPORTUNITIES AND LIFE SKILLS

This section explains what support is provided in relation to employment and life skills for people with special needs. It is noted that increasing the employment rate for people with special needs and disability promotes social inclusion. We appreciate that not all can realistically participate in employment, but resources can still be directed to enabling their inclusion in the community¹⁶.

7.1 Employment Opportunities

The Jersey Employment Trust (JET) is a charitable trust whose primary role is to assist people with a disability to find and sustain open employment. JET provides employment support services which includes: helping people find suitable employment opportunities; negotiating with employers and on-the-job training and support.¹⁷ JET is funded by the Health and Social Security Departments.

STEPS is a multi-agency project and is funded by the Social Security Department. It involves partnership working between JET, Jersey Mencap, Autism Jersey, MIND Jersey and other agencies. The aim of the project is to enable individuals with specific needs, disability or long-term health conditions to progress on a vocational pathway. This may include life skills training, pre-employment or educational courses and volunteering opportunities¹⁸.

Jersey Employer's Network on Disability (JEND) was formed in 1998 and is made up of a number of employers in Jersey who are committed to providing jobs for individuals with a disability. These employers work in partnership with local support agencies and charities to maximise work experience and employment opportunities¹⁹.

7.2 Life Skills

Les Amis offer life skills training to its clients via the Town Service. The Town Service focuses on giving each of its 29 residents the everyday life skills with the aim of them being able to live more independent lives in the community. Although the Town Service is concerned mainly with Les Amis younger residents with Downs' Syndrome, Autism and other conditions including head injuries and learning disabilities, it also supports older people.²⁰

Highlands College offers an Entry and Life Skills Course which is designed for students with learning difficulties and/or disabilities. The majority of the students transfer from Mont à L'Abbé School with a few transferring from mainstream school. Students can study for up to three years full time although work preparation is an important part of the third year. Some students access the course part-time if they are not able to attend full-time.

Students may join the course from the age of 16, with some joining at 18. After completing the 3 year course, leavers range in age from 19 – 21 year.

Highlands College liaise extensively with the Jersey Employment Trust throughout a student's time in college in preparation for when they leave college. The College explained that it has also

¹⁶ Improving the Life Chances of Disabled People, Prime Minister's Office, 2005

¹⁷ Information sourced from JET website at www.jet.co.je

¹⁸ Information sourced from JET website at www.jet.co.je

¹⁹ Information sourced from JEND website at www.jend.je

²⁰ Information sourced from Les Amis website at www.lesamis.org.je

established good links with other agencies which adds to the wraparound support offered to students.

Highlands College also said that it is sometimes perceived by parents that JET should offer a service that occupies clients for much of the week. However the College explained that this is not the aim of JET and with the increase in referrals to the service, it is unlikely that they could offer much more than they are doing without a further injection of funding²¹.

²¹ Correspondence received by Head of Guidance and Support, Highlands College, dated 27th March 2015

8. RESPITE DEMAND

Demography is changing due to higher life expectancy at all ages and abilities. This has led to an increasing number of older adults with disabilities and a growth in the number of people with severe and profound disabilities who require lifelong care. In the early 1930s the average life expectancy of a male with learning disabilities was 15 years old and 22 years old for a woman. Nowadays, many people with learning disabilities live well into middle and older age, whereas previously, achieving old age was rare²².

Furthermore, the prevalence of people with disabilities is increasing with advances in medical technology and the ageing population. People with disabilities are, on average, more likely to experience a broad range of health problems. Families also suffer problems related to the informal care of those with disabilities including increased stress-related physical and emotional illness²³.

8.1 Statistical Information

The number of people with disabilities in Jersey is unknown. The 2013 Jersey Annual Social Survey (JASS) indicated that around 10% of the Jersey population had a long-lasting condition or difficulty that significantly affected their ability to carry out normal day-to-day activities (but this included conditions relating to old age)²⁴.

Using data collected by the JASS survey, the table²⁵ below gives the approximate prevalence of a range of conditions or difficulties experienced by Islanders. It should be noted that the JASS is a postal self-completion questionnaire and therefore it is likely to under-estimate disabilities that might affect a person's ability to complete the form:

	Percent
Blindness or a serious visual impairment	1%
Deafness or a serious hearing impairment	3%
Physical impairment (e.g. wheelchair user and/or difficulty using arms or hands)	4%
Learning disability (e.g. autism, Down's syndrome)	1%
Mental Health condition (e.g. depression or severe phobia)	3%

The previous Panel's report on respite for children and young adults noted that accurately assessing the number of families who have children with disabilities who may need respite is a difficult task. A report in 2011 commented that there is "no comprehensive data about the number of children and young people with disabilities in Jersey, or about the nature of their disability"²⁶. The previous Panel found that babies born with special needs are not logged or monitored with respect to support services required in later life. Young children who receive a diagnosis are similarly not registered onto a database to "flag up" key milestones at which point the family might require respite care or other support services²⁷.

²² Health Needs Assessment Report: People with Learning Disabilities in Scotland

²³ Promoting the health of people with physical disabilities, R. Smith, Health Economics, 2000

²⁴ Health Profile for Jersey 2014

²⁵ Health Profile for Jersey 2014

²⁶ Children And Young People: A Strategic Framework For Jersey (R.133) - 2nd November 2011

²⁷ Public Hearing with the Minister for Health and Social Services, 27th February 2012, page 23

As a result of its findings, the previous Panel recommended that an information management system was developed to capture the needs of the Island's families who care for children with special needs. The Panel also suggested that this data should be captured from existing sources of knowledge such as healthcare and education professionals.

The Minister accepted the recommendation and explained that a framework for collecting, collating, monitoring and developing performance within all areas of the children's service was already contained within the "Children's Services – Improvement Plan for 2012 – 2013". It is unclear whether this work has been taken forward as the Panel was advised in December 2014 that all outstanding actions contained within the improvement plan had been assimilated into either the "Children and Young People's Strategic Framework Delivery Plan" or the "Children's Services Business Plan".

8.2 The Disability Strategy

The Chief Minister's Department is currently working on a Disability Strategy for Jersey, which will gather information on the experience of local people living with a disability. From this knowledge, a Disability Strategy will be developed during 2015/2016. It is anticipated that a first draft will be issued for consultation in early 2016²⁸.

We were told that there are a range of issues and challenges surrounding disability which include respite. One of the reasons for developing a strategy is to understand the extent of the issues and challenges by issuing a postal survey to 10,000 households and holding a set of focus groups. The strategy will illustrate the issues raised, and in response to the levels of concerns expressed explain how the work should be progressed using the resources available²⁹.

KEY FINDING 1: There is no cohesive information regarding the breadth and depth of disability in Jersey. Information is held within different agencies including the Health and Social Services Department, primary care providers and the Social Security Department but there is a lack of concrete data. Understanding the breadth and depth of disability in Jersey is a key element to developing a strategy, without it, services will not be tailored to meet people's needs and there will be an inability to plan for future demand.

RECOMMENDATION 1: By the end of 2015, a framework for collecting and collating data and monitoring and developing performance within both children and adult services should be developed. This should be developed using data obtained from the Disability Strategy and in accordance with an information management system which complements collecting information from other Departments.

8.3 How many respite beds are there in Jersey?

Adult Services

Within adult services there are five respite beds in total, but this will decrease to four at the end of July 2015. The result of this is that there will only be one residential respite bed which caters for wheelchair users after July 2015:

²⁸ Written Question to the Chief Minister, 28th April 2015

²⁹ Public Hearing with the Assistant Chief Minister, 20th March 2015, page 11

Organisation	No. of Beds
Mourant Lodge	4
Jersey Cheshire Homes (will discontinue the service after July 2015)	1
CURRENT TOTAL	5
TOTAL AFTER JULY 2015	4

Children's Service

Within the children's service there are eleven respite beds in total:

Organisation	No. of Beds
Oakwell Respite Home	4
Eden House	3
Maison Allo	4
CURRENT TOTAL	11

Oakwell respite home provides for children with severe mobility problems or profound and multiple learning difficulties. The four residential respite beds at Oakwell are all wheelchair friendly. Eden House caters for children on the autism spectrum and/or with associated complex developmental needs. It is understood that Eden House is currently being fully utilised to accommodate a family in crisis. Maison Allo provides for children with mild to moderate learning disabilities and is a regulated provision.

We raised the issue of whether there were more services available for children than for adults and it was acknowledged by the Department that this was a current challenge:

Deputy J.A. Hilton:

Could it possibly be that you may have a young person who is a week off being 18 who is receiving a good service at the moment, but they are going to transition into Adult Services and their care, or the service being offered to them, is going to be cut because of the situation with the lack of residential beds available?

Director of Adult Services:

Today that is possible. Today that is possible, so that is a real challenge for us and sadly it takes me back a few years to when I was first doing this business case, because that was the challenge, that we were not providing the quality and access to services in Adult Services that people were experiencing in children's.³⁰

KEY FINDING 2: There are eleven respite beds in the children's service and five (which will decrease to four after July 2015) within adult services. There is a danger that users of the children's service will have insufficient facilities for overnight respite care when they reach 18 and

³⁰ Public Hearing with the Minister for Health and Social Services, 9th February 2015, pages 34 and 35

enter into adult services. The disparity between children and adult services may increase pressure on adult services and lead to overreliance on outreach and inreach services.

8.4 How many will require adult respite services?

When the Panel compared the number of residential respite beds within the children's service to adult services the disparity between the numbers of beds was a concern as there are just over twice more beds within the children's service. The Panel are also concerned that there are double the number of beds available which cater for wheelchair users in the children's service.

Highlands Residential Care Home had previously provided four respite beds for people with complex and physical disabilities which were all wheelchair friendly. The Director of Adult Services told us that three residential beds (which the Panel believes should cater for wheelchair users) are required to meet the demand for short break services³¹:

Deputy J.A. Hilton:

In your opinion, how many beds do you think that we need today to fulfil the need that is currently out there to enable families to have a break?

Director of Adult Services:

I think we can sustain the residential breaks on 3 beds. I think, if we were to better respond to the holiday support, we ought to be looking at going back to 4 to enable that to happen³².

The Panel is concerned that there are not enough respite beds within adult services to cope with the demand. We have been informed that the Health Department is looking at other ways to increase the number of beds (which is explained further on in the report) but this should not be to the detriment of any other respite service.

KEY FINDING 3: Three residential beds in adult services are required to meet the demand for short break services for wheelchair users. From the end of July 2015 when Cheshire Homes will no longer provide such a respite bed, there will only be one respite bed which caters for wheelchair users.

The Panel is already aware that there is a current lack of statistical data in relation to people with disabilities, but wanted to find out how many current users of respite required wheelchairs and the number of people who would be coming through the system into adult services. The Panel was provided with information from the Le Geyt Centre which explained that there are currently 13 wheelchair users attending the service, 8 of which are living at home and may require short breaks, including residential respite.

The table on the next page provides the number of students currently attending Mont à L'Abbé Primary and Secondary School. We were advised that, in addition to the 11 students in the table, quite a few students need physical support or have other mobility difficulties³³.

³¹ Public Hearing with the Minister for Health and Social Services, 9th February 2015, page 24

³² Public Hearing with the Minister for Health and Social Services, 9th February 2015, page 27

³³ Statistics obtained from the Headteacher of Mont à L'Abbé School

Age bracket	No. of wheelchair users
5 – 6	3
6 – 7	
7 – 8	
8 – 9	2
9 – 10	
10 – 11	
11 - 12	1
12 – 13	
13 – 14	2
14 – 15	
15 – 16	2
16 – 17	
17 - 18	1
Total	11

Good data management would enable the Health Department to monitor how many children and adolescents with complex disabilities are entering into the age bracket looked after by adult services (18+). It would enable service providers to determine when there may be an influx of families moving into adult services thereby helping to plan for an increase in demand. One parent the Panel spoke to explained that projecting future demand was needed and that there is currently a lack of cross departmental working:

“...there is no joined-up thinking. You have only got to go to Mont à L’Abbé school, be it the primary one or the secondary one, and then you will see what need is coming through the system. This has never been done but what tends to happen, you get a kneejerk reaction. Like you have got ... using Mourant Lodge their wheelchair access, now you have probably got about 5 families waiting to use it and they are all quite a similar age. So they have all come through the educational system and nothing whatsoever has been put in place. Now I find that a massive flaw³⁴”.

KEY FINDING 4: Evidence suggests that the need and demand by wheelchair users for respite will increase rather than diminish with three more wheelchair users entering into adult services within the next three years. The Panel understands that there are several families waiting to access the wheelchair friendly room at Mourant Lodge. It is also noted that there are a number of students at Mont à L’Abbé School who need physical support or have other mobility difficulties, and therefore are likely to require ground floor residential respite facilities when they enter into adult services.

The Panel also question what contingencies are in place if a physically disabled service user was to go into crisis. It is understood that often respite services are disrupted as a result of homes being used for emergency care placements³⁵. If there are insufficient beds available to cope with

³⁴ Private Hearing with Witness 3, 20th February 2015

³⁵ Respite Care for Children and Young Adults (S.R.2/2012), 26th April 2012, page 28

families going into crisis, respite homes will almost be under constant threat of being used as substitute emergency care or long-term care facilities in times of crisis.

KEY FINDING 5: There is currently no spare capacity to cater for emergency cases. If a service user was to go into crisis, other users may have reduced access to residential short break services.

9. FUNDING RESPITE SERVICES

This section explains the financial aspects for respite care in Jersey. It includes what funds were allocated in the previous Medium Term Financial Plan and what has been allocated in the current plan in relation to adult services. We also explain the Long-Term Care fund and its interaction with respite services.

Currently, the Health Department has a budget of £561,261³⁶ which is spent on residential, outreach and inreach services:

- Community short breaks and outreach - £284,245
- Mourant Lodge - £211,020
- Jersey Cheshire Homes - £66,000

There are 21 individuals³⁷ and families accessing residential breaks and 28 families accessing outreach/inreach services. In 2012, the budget was £567,000 which indicates that over the last 3 years the budget has decreased slightly³⁸.

In relation to day services and the Le Geyt Centre, the budget is £1.1 million which includes a number of individual bespoke packages³⁹.

9.1 The Medium Term Financial Plan 2013 - 2015

The Medium Term Financial Plan (MTFP) 2013 – 2015 explains that £4 million has been allocated to Adult Care Homes within the long-term capital plan 2012 - 2032. It also explains that there are several key issues that require addressing within the special needs service and the £4 million project aims to deliver the following improvements⁴⁰:

- Fit for purpose home for life for people with significant and complex needs
- Appropriate day services for people with learning disabilities, integrated into the community
- Development of appropriate day time service for people on the autistic spectrum
- Appropriate residential setting for specialist assessment and treatment of vulnerable adults

When we met with the Health Minister he explained that £1.2 million had been allocated to address the risk factors at Orchard House (a mental health facility), £100,000 allocated to Learning Difficulties Day Service Strategy and £700,000 allocated to a centre for Autism Jersey⁴¹ (the latter two sums both relate to the future of the Le Geyt service which is explained further on in the report).

The MTFP also contained funding, as per P.82/2012, of £2,440,000 for older adults (dementia) services, which included carers support and the Jersey Online Directory. The Panel is disappointed that a proportion of this investment has been phased to enable the Health

³⁶ Commissioning Intentions Paper: Whole System Redesign of Short Breaks Services

³⁷ Updated figure taken from Whole System Redesign of Short Breaks Services - Update

³⁸ Public Hearing with the Minister for Health and Social Services, 9th February 2015, pages 31 and 32

³⁹ Public Hearing with the Minister for Health and Social Services, 9th February 2015, page 33

⁴⁰ Medium Term Financial Plan 2013 – 2015, page 255

⁴¹ Public Hearing with the Minister for Health and Social Services, 4th April 2015, page 3

Department to manage the 2% savings agreed in the 2015 budget. The Panel was informed that the funding will be used in 2016.

9.2 The Medium Term Financial Plan 2016 – 2019

The second MTFP is being proposed in two stages. Part one was lodged on the 14th July 2015. It covers income targets and spending limits to 2019 and detailed departmental spending for 2016. The second part of the plan, which will contain detailed departmental spending for 2017-2019, will be published by the end of June 2016.

The MTFP explains that £0.4 million in 2017 and £1.8 million in 2019 additional funding growth will improve and develop mental health services. Investment will result in a single integrated “adult” service which incorporates specialist expertise for people with learning disabilities and autism⁴². It is anticipated that the annex to the MTFP will provide more detail on these investments.

9.3 The Long-Term Care Scheme

The Long-Term Care Scheme collects contributions from local residents and makes benefit payments to adults who have long-term high-level care needs. To qualify for the benefit, people must be assessed by a registered health or social care professional as needing permanent help with daily living activities. The assessment allocates people on one to four care levels⁴³:

- Level 1 – needs a moderate level of support
- Level 2 – needs a high level of support
- Level 3 – needs a very high level of support
- Level 4 – needs an extremely high level of support

Once someone has qualified for the scheme, they are required to meet an amount of standard care costs themselves, if they can afford to. The standard care cost has been set at £52,120. Once accepted onto the Long-Term Care Scheme their care cap will start to accrue even if they are not paying any money towards it themselves⁴⁴.

The value of the £52,120 care cap is the same regardless of someone’s care level. However, the number of weeks it would take to reach the care costs cap ranges from 53 weeks at the highest level (level 4) up to 148 weeks at the lowest care level (level 1)⁴⁵.

If someone has long-term care needs they (or their carer) are required to contact the long-term care team at the Health Department to organise a care needs assessment. Once this has been undertaken, the long-term care team passes the information on to an adviser at the Social Security Department who would then start the claim process⁴⁶.

9.4 The Long-Term Care Scheme and Respite Care

If someone is living at home, they can still qualify for the long-term care benefit. For example, this could be a package of care provided in the home combined with receiving unpaid informal care

⁴² Medium Term Financial Plan 2016 – 2019, page 65

⁴³ Long-Term Care Scheme – General Information booklet, Social Security Department

⁴⁴ Public hearing with the Minister for Social Security, 21st April 2015, page 19

⁴⁵ Long-Term Care Scheme – General Information booklet, Social Security Department

⁴⁶ Long-Term Care Scheme – General Information booklet, Social Security Department

from a friend or relative. If people are receiving a package of care delivered in their own homes by an external provider, then to be covered by the scheme this has to be delivered by a care provider that is on the approved provider list⁴⁷. If the care includes unpaid informal care, then the long-term care claim will normally include a separate sum of money for respite care to give the informal carer a break.

The Minister for Social Security explained that under the Long-Term Care Scheme, the respite allocation just covers the support required to give carers a break from time to time during the year. This is on top of the daily and weekly support that is part of their regular care package. This means that the services referred to as respite services within this report fall into two separate parts of the total funding available from the Long-Term Care Scheme. In addition, some services such as day services and some respite provision are currently provided free by the Health Department and have not yet been incorporated into the overall budget for the Long-Term Care Scheme.

In terms of respite, the scheme only provides for people who are receiving care at home, and the calculation is worked out on the basis of how much the informal unpaid carer is providing to that cared-for person⁴⁸.

The assessment process asks for every single characteristic of care which is quantified and scored. A professional health care assessor uses a resource allocation system to help determine how much respite an individual should get according to their care level. The Social Security Department has set respite up to 6 weeks annually, depending on how much informal care is provided⁴⁹.

Currently respite services are allocated by the Health Department and are free at the point of delivery, and individuals are not means tested. The Long-Term Care Scheme is changing this, as individuals over 18 are now entitled to claim the long-term care benefit and could be responsible for “commissioning” their own services⁵⁰. The Managing Director of Les Amis made the following comments on the scheme:

“We are concerned that the principle of giving more ‘buying power’ to families may cloud the reality that some parents will not understand or work together to commission a residential provision. It is also a concern that the families that have the way and means to organise themselves will get what they want and those more disorganised will end up with nothing. What one is correct? The whole thing needs more clarity and explanation not only to families but service providers also⁵¹”.

One parent the Panel spoke to explained some difficulties in understanding what moving to the Long-Term Care Scheme would mean, and his concerns about receiving outreach care:

“Yes, I am so mixed up because my social worker was saying I need to make up my mind whether to stay with Social Security or go to the long-term care before we are allowed to sort anything out, but other organisations are coming on board and they are looking. What they think they can help me with is outreach. Because they do not have the bed to support

⁴⁷ Long-Term Care Scheme – General Information booklet, Social Security Department

⁴⁸ Public Hearing with the Minister for Social Security, 21st April 2015, pages 4 and 5

⁴⁹ Public Hearing with the Minister for Social Security, 21st April 2015, page 5

⁵⁰ Commissioning Intentions Paper: Whole System Redesign of Short Break Services

⁵¹ Mr S Findlay, Managing Director of Les Amis – email correspondence 19th February 2015

me they are looking at outreach and using my home, which is all right but that can be up to 7 different people. But it is my home. It is a little hard to take on board letting strange people ... well, until you get to know them, coming into your home, caring ... as well as looking after my son, knowing if they are capable of that, but also in my own home, cooking him a meal or whatever, you know, it is worrying⁵²”.

KEY FINDING 6: Some families and carers have been left confused about the Long-Term Care Scheme and what it would mean for them in terms of respite care. The principle of giving people more “buying power” may lead to inequalities of distribution due to a lack of understanding about how the system works.

KEY FINDING 7: The Social Security Department has set respite care at six weeks for the year in relation to the Long-Term Care Scheme. However, there may not be sufficient overnight residential respite provision within Health and Social Services to allow for 6 weeks of respite care. This may lead to families having no other choice but to access outreach and inreach services.

Individuals are required to meet the first £52,120 amount of standard care costs themselves if they have a significant income or assets above the disregard limit of £419,000. It is understood that the budget currently held by the Health Department to provide respite services could in the future be transferred to the Long-Term Care Scheme with individuals then funding their respite through the scheme. Therefore, someone who is not paying for respite today could be paying for respite until they have reached the care cost cap of £52,120⁵³.

This is also the case if a person has been in the Island for less than 10 years. He or she would need to fund all of their respite care until eligible for the benefit after 10 years residence although some assistance may be available through the income support system. This can be contrasted with the present position where respite costs are met by the Health Department. Disability or chronic illness can strike anyone at any stage of life and often brings greater costs to a family. Therefore it is foreseeable that a family in those circumstances will neglect respite opportunities in order to fund more immediate needs. Ultimately this could lead to the carer's burnout sooner rather than later with the result that the disabled person may require more intensive or residential care at an earlier stage than might otherwise have happened.

⁵² Private Hearing with witness 1, 16th February 2015

⁵³ Public Hearing with the Minister for Social Security, 21st April 2015, page 13

10. CHALLENGES WITHIN THE RESPITE SERVICE

This section focuses on the challenges and difficulties within the respite service we have been made aware of during the course of our review.

10.1 Provision of adult respite facilities compared to children's respite facilities

Special needs children receive a high quality of schooling at Mont à L'Abbé School and regular social interaction offered by children's respite which includes Oakwell, Eden House and Maison Allo. This quite rightly sets up an expectation of an adult life that is similarly full and dynamic, with access to a similar range of activities, learning experiences and individualised support.

However, it would seem that more services are offered to children, or that there are more services available within the children's service than there are in the adult service. Oakwell respite home caters for children with severe mobility problems or profound and multiple learning difficulties and all of its rooms are wheelchair friendly. Since its refurbishment in 2013/2014 the home now includes a new sensory room and improved hydrotherapy pool facilities. We note that none of the respite homes in adult services have hydrotherapy pool facilities. Work is currently being undertaken at Cheshire Homes to refurbish their pool, however, the home will stop providing a respite bed at the end of July 2015.

KEY FINDING 8: More services are available within the children's service compared to adult services. For example, one of the respite homes within the children's service has a hydrotherapy pool facility.

In 2013, parents and staff from the Health Department attended workshops designed to find out what parents of young adults with disabilities wanted in regards to respite. The workshops also included users of respite who were able to contribute to the discussions. The response from parents was that an "Adult Oakwell" was required. In other words, a small bespoke home where staff would look after young adults, attending to both their physical and social needs⁵⁴.

Andium Homes had been working on proposals to complete the regeneration of the former Le Squez estate. They were progressing with a proposal from the Health Department for a new 5 bedroom respite facility and subsequently incorporated this into the proposals for the final phase of Le Squez. In March 2014 Andium Homes offered the Health Department and Jersey Property Holdings terms for the delivery of the proposed new respite facility but were told by the Health Department that the need for such a facility had changed and the offer was not pursued⁵⁵.

One parent who attended the workshops wrote to the Panel and explained: "*The result of these workshops culminated in a presentation to senior members of staff from H&SS and various politicians. This was fruitless as our wishes were ignored. We had been told that there was a distinct possibility of a bespoke respite home being built at Le Squez, when parents asked about the progress on the home months later; we were informed "We were told that parents did not want this, so it is not going ahead". We don't understand where this came from, as it clearly was what parents wanted*⁵⁶".

⁵⁴ Written Submission, received 3rd March 2015

⁵⁵ Public Hearing with the Minister for Health and Social Services, 9th February 2015, pages 24 and 25

⁵⁶ Written Submission, received 3rd March 2015

The Panel finds it unacceptable that a decision not to go ahead with the bespoke respite facility was not recorded in a formal manner or communicated to service users.

When the Panel spoke to Les Amis they agreed that if a bespoke adult respite home was required it could assist in partnership with Le Vaux Housing Trust: *“If there is a need to develop further provision for respite then we can assist in partnership with Le Vaux who only need a piece of land and are willing to develop something similar to Mourant Lodge. I have read that Senator Green has put a purpose built provision at Le Squez back on the cards. This would be a very costly exercise for the States and it comes with a long term commitment financially. We could work in partnership to develop what is needed for families with little cost to the tax payer reducing the risk to the States being stuck with a building they do not need or can use if people move towards a community based outreach respite model in the future⁵⁷”*.

It is recognised that overnight residential based respite services (as opposed to home based respite or outreach/inreach as it is sometimes referred) are expensive to develop and maintain as a model of care. However, evidence suggests that there is, and will continue to be, a strong demand for overnight residential based respite in order to provide the appropriate range of respite services especially for those with complex needs.

KEY FINDING 9: No audit trail has been found of the decision to cancel plans for a new bespoke adult respite home. Evidence gathered during the review shows that there is and will continue to be a strong demand for this kind of respite care in Jersey.

RECOMMENDATION 2: The Minister for Health and Social Services should ensure that overnight residential respite will continue to be provided to families and carers without having a negative impact on other services. In particular the Minister should ensure that wheelchair users have sufficient facilities which the Panel considers should have three accessible beds. The Department should work in partnership with organisations such as Les Amis who have offered to develop what is needed for families.

10.2 Home based respite compared with overnight residential based respite

Home based respite care includes outreach and inreach services. These are domiciliary-style services which include taking people with complex needs either out into the community (outreach) or supporting them in their own home (inreach). The Director of Adult services told us that these services have developed more readily in recent years⁵⁸.

Choice and a variety of options and alternatives for respite care are important. Although we are not unsupportive of outreach and inreach services being developed as they give families greater choice, we believe that the option of overnight residential respite care should be maintained. Therefore, we consider that home based respite care should be an additional option rather than a replacement for residential respite services. The needs and circumstances of people with complex needs vary and this should be reflected in the types of respite services available. The development of home based respite care in addition to residential based respite care means that people can have tailored and appropriate care in response to their needs.

⁵⁷ Mr S Findlay, Managing Director of Les Amis – email correspondence 19th February 2015

⁵⁸ Public Hearing with the Minister for Health and Social Services, 9th February 2015, page 19

KEY FINDING 10: Home based respite services (outreach and inreach) have developed more readily in recent years whilst residential based respite services have contracted. The Panel believes that these types of respite services should be additional for families rather than a replacement for residential based respite.

10.3 The transition process from children's to adult services

Young people face many challenges when preparing for adult life, but for children and young people with complex physical and learning disabilities, there are many additional challenges. For example, in many cases, the health needs of young people will have been provided by the Paediatric team at the Hospital this then changes to being cared for in an adult environment⁵⁹. They also face changes in education, respite facilities and social workers.

It is important that the co-ordination of the transition process is carried out through a "transition plan". This should start at 14 years of age, or earlier. From speaking to families and carers, the Panel has found that the transition process has been variable. The families and carers of these young people told the Panel that they have often been confused by the lack of information, support and services available in Jersey to meet their complex health needs:

"It seems to be that our children are children until they turn 18, so 17 and 11 months we can have the support through Speech and Language, we can have the support through respite at Oakwell, we can have physio, we can have occupational therapy and then suddenly at 18 the door closes and that child has become an adult and for all intents and purposes they have lost that disability, they do not need that support any more. But they still need all of that, we still need it and it just ... it goes completely⁶⁰."

".....I kept saying: "Let us plan for J an adult" you cannot plan nothing until he is 18. This is true. This is what I got told. You cannot plan nothing until he is 18. You have to wait until he is 18".⁶¹

"The transition from Child Services to Adult was going very well, all planned out, then there was another emergency in Child Services and J got told ... we got told that if we did not do it in 2 weeks when it was meant to be over a 3-month period he would lose his respite, the transition would stop and we would have to start again in 3 months' time. That was Child Services. Adult Services was fantastic. Again the staff member from Child Services went and stayed with J at Adult Services over a couple of weeks to help him transition. He did the transition in 2 weeks. It worked wonders. It was the staff. Not the way it was run or the management. It was the staff that did everything to help J"⁶².

The Health Department acknowledged that in some cases there were issues with the transition process. The Director of Adult Services explained: *"I think there is good and bad in there, because much as we have endeavoured to be consistent, we have still not cracked getting this right totally yet. Sometimes circumstances are beyond our control in regards to staff that are involved, so if staff leave, for example, who might be at the point of a critical point with a family. We have some*

⁵⁹ Site Visit to Mont à L'Abbé Secondary School, 6th March 2015

⁶⁰ Private Hearing with witness 4, 20th February 2015

⁶¹ Private Hearing with witness 1, 16th February 2015

⁶² Private Hearing with witness 2, 16th February 2015

really good examples of transition planning and we have some examples where it has been really difficult for the individuals and the families⁶³”.

Within the previous Panel’s review of respite for children and young adults, it recommended that transition planning starts as early as possible and children’s and adult’s services communicate better to ensure services do not “drop off” at 18 years. This was accepted by the Minister who advised that the Transition Policy would be reviewed with an aim to improve both the process and the communication required for families. The Minister also advised that with the inception of the Health White Paper, there was a proposal for an additional social worker within the Adult Social Work Team to provide a lead on transition planning.

The current Panel requested an update on the previous Panel’s recommendation, and in response, the Department explained that the planning cycle for the Health White Paper included business cases to be funded through the current Medium Term Financial Plan (MTFP). This process included future planning, referred to as the ‘Transition Plan’ which outlined key information in regard to the next MTFP 2016 - 2019. This included a bid for two additional social work posts within Adult Services. One to support transition planning for young people who will require continued support in to their adult life, and the second post to support the increase in numbers of people on the autistic spectrum.

This is in an attempt to seek to improve both the available resource and consistency of support to individuals and their families throughout the period of transition. Presently, transition is managed as a core responsibility within the Adult Social Work Team⁶⁴.

The Panel raised this issue with the Director of Adult Services who acknowledged that in order to provide a transition service effectively, the two additional social worker posts were required⁶⁵. It is noted that these bids are subject to the current financial constraints and can only be advanced if resources can be secured through the MTFP 2016 - 2019 process⁶⁶.

KEY FINDING 11: The previous Panel highlighted significant issues with the transition process in 2012. It appears that the process is still variable and families and carers are still being left confused when their child reaches the age of 18. The Panel has been told that in order to provide an effective transition service, two additional social worker posts are required.

RECOMMENDATION 3: The Panel was told that resources must be secured through the Medium Term Financial Plan 2016 – 2019 for two additional social worker posts if an efficient and effective transition service is to be provided. The Health and Social Services Department should develop new and innovative ways of working in order to provide an effective transition service within existing resources and not solely rely on securing funding for additional staff.

10.4 The value placed on family carers

Caring for a family member with a disability is a lifelong commitment, which continues even when the person is living away from the family home. Carers make a vital contribution to the lives of people with disabilities, often providing most of the support they need. They are a crucial resource for ensuring that people with disabilities can live in the community. There is no precise data on

⁶³ Public Hearing with the Minister for Health and Social Services, 9th February 2015, page 39

⁶⁴ Correspondence received from Interim Managing Director, Community and Social Services, dated 15th January 2015

⁶⁵ Public Hearing with the Minister for Health and Social Services, 9th February 2015, pages 39 and 40

⁶⁶ Correspondence from Interim Managing Director, Community and Social Services, 15th January 2015

numbers, but the UK has estimated that some 60% of adults with learning disabilities live with their families⁶⁷. It is therefore imperative that we recognise the extent of carers' contribution and its value.

A sustainable and reliable respite service is important in order to help prevent families reaching crisis point due to the stress of full-time caring. There have been times within the children's service when a crisis situation has arisen and the children have been placed in specialist care in the UK at significant cost to the States.

The Health Department must ensure that carers receive the right support to help them in their caring role, obtain relevant information about services and know who to approach for advice and help. Within the adult service, respite is booked on a three month basis whereas in the children's service parents can book up to a year in advance⁶⁸. This change in the booking system between children's and adult services must be frustrating for some parents particularly if they have work commitments. Carers could be supported more if the service offered more flexible booking arrangements which take account of choice and fit in with carers commitments.

It is also important that carers have the opportunity to take a holiday. Respite services must have the sufficient capacity to offer flexibility for an annual holiday break as well as the provision of regular overnight respite throughout the year. One parent told us: *"...we prefer to save our allocation for longer respite periods to have holidays together and with friends. To achieve this, as there is nowhere for A to go for say 5 or 6 consecutive nights, we now have the opportunity of having carers in our own home"*⁶⁹.

The Panel note that work has been undertaken to try and improve support for carers in Jersey. The new 2013 - 2016 Carers' Strategy, which builds on the original Carers Strategy (2009), involved consultation with local groups and charities that support carers. It sets out the framework for improving support for carers and its vision is: "To comprehensively recognise value and support carers in Jersey."⁷⁰

RECOMMENDATION 4: By the end of 2015, the Health and Social Services Minister should publish an update on the Carers' Strategy 2013 - 2016. This should include what progress has been made since it was drafted in 2013.

10.5 The purpose of the Service User Forum

The Service User Forum was established by the Chief Minister's Department at the request of service users who wanted to be able to voice their concerns. The Forum meets on a quarterly basis and is made up of a group of people across the community⁷¹.

When the Panel spoke to the Chairman of the Service User Forum, Senator Routier, he explained that the purpose of the Forum was a "sounding board" and that *"...it is just a discussion to hear all these things and the Health Department are the ones and the Social Security Department are the ones who need to react to that. We are there to make sure these things are heard"*⁷².

⁶⁷ Valuing People: A New Strategy for Learning Disabilities for the 21st Century. Department of Health, 2001

⁶⁸ Private Hearing with witness 1, 16th February 2015, page 6

⁶⁹ Written Submission received 22nd February 2015

⁷⁰ Written Question by Deputy Higgins, 2nd December 2013

⁷¹ Public Hearing with Senator Routier, 20th March 2015, pages 3 and 4

⁷² Public Hearing with Senator Routier, 20th March 2015, page 9

RECOMMENDATION 5: The Chief Minister, through his Assistant Chief Minister, should engage more closely with the Service User Forum and use it as an opportunity to develop policy as it brings together people who have personal experience of multiple and complex problems. The Chief Minister’s Department should publish formal records of the Service User Forum’s meetings which include specific actions to be taken forward.

10.6 The Le Geyt Centre is no longer fit for purpose

The Panel visited the Le Geyt Centre during the review and noted that its last refurbishment was carried out 15 years ago in 2000. We received a paper from the Health Department which explained that the current base at the Centre is no longer fit for purpose and does not have adequate facilities to meet the long-term needs of the service users⁷³.

Le Geyt service users are split into two categories – essential service users and non-essential service users. Essential respite users are defined as those who live at home and non-essential service users are those that are either in Health and Social Services residency or cared for in the private sector. The paper explains that due to levels of complexity regarding the support required, the current budget would be insufficient to meet the needs of all current essential respite and non-essential service users. Furthermore the service would not be able to meet the forecasted demand for placement from 2014 to 2017 arising from transitioning young people⁷⁴.

The Panel was advised that work had been undertaken by staff at Le Geyt and its service users regarding a vision for the future. Its vision was for smaller bespoke premises to be provided around the Island with the Le Geyt Centre building becoming an autism centre. The Health Department has detailed the proposed change and vision for the future in a resource allocation form which indicates the funding required.

The purpose of moving into smaller bespoke premises is to move away from bringing large groups of disabled people together in a single setting because large groups can lead to difficulties for individuals who are sensitive to noise or have issues regarding visual spatial awareness⁷⁵.

When the Panel spoke to the Health Minister he confirmed that £700,000 had been allocated to fund a centre for Autism Jersey. The Minister explained that the project would cost more than £700,000 but that was the figure currently allocated and partnership working between the Department and Autism Jersey would develop the centre⁷⁶. The Panel was also informed that £100,000 had been allocated to Learning Difficulties Day Service Strategy which would assist with developing the smaller bespoke premises around the Island.

The Department has not explained why it has begun piecemeal planning in the absence of an overarching strategy to replace the services provided at the Le Geyt Centre.

KEY FINDING 12: The Le Geyt Centre is no longer fit for purpose as a day centre and does not have adequate facilities to meet the long-term needs of the service users. Plans have been developed for smaller bespoke premises to be provided around the Island with the Le Geyt Centre building becoming an autism centre.

⁷³ Summary Annual Business Planning Resource Allocation From, 2015

⁷⁴ Summary Annual Business Planning Resource Allocation From, 2015

⁷⁵ Paper on Special Needs Days Services: Requirements for 2013 onwards

⁷⁶ Public Hearing with the Minister for Health and Social Services, 24th April 2015, page 4

RECOMMENDATION 6: The Minister for Health and Social Services should ensure plans for the future of the Le Geyt Centre are fully costed before June 2016 when the second part of the Medium Term Financial Plan 2016 – 2019 will be lodged. The Panel also recommend that key decisions regarding this development are formally recorded and published so that service users are able to track its progress.

It is hoped that the Le Geyt vision will also improve the current issues with transport to and from the facility. There is a lack of appropriate transport for those most severely disabled accessing the service who often spend a lot of time when they are collected on the bus travelling around collecting other service users. Those service users are also sometimes unable to access the same opportunities as other day service users because there is a lack of appropriate transport⁷⁷.

Director of Adult Services:

*“..there are 2 separate things here. One is around general transport, getting in to Le Geyt and back home, and we are hoping that the more geographically located services reduces some of that pressure. The second is access to appropriate transport, while you are at the service, to go out and enjoy the day and take part in the community. I do know that today we have an issue with one of our vehicles at the Le Geyt Centre which we are working to try and resolve. That has put us under some additional pressure because we have not had the available transport that we would normally have”.*⁷⁸

The Panel understand that the States’ policy is that vehicles are not kept past 7 years old, but the vehicle used to transport service users at Le Geyt is in its ninth year. It was acknowledged that the vehicle should have been replaced but financial constraints have meant that there are no funds to be able to replace the vehicle. The Department is currently looking at lease arrangements to acquire a vehicle rather than purchasing a new one⁷⁹.

KEY FINDING 13: The transport provision to take service users to and from Le Geyt Centre is not working properly. Many of those most severely disabled spend a lot of time on the bus collecting other service users. Financial constraints have meant that there are no funds to replace the current vehicle which is in its ninth year in service.

RECOMMENDATION 7: The Health and Social Services Department should investigate ways of providing a better transport service for users of day services including working with the Voluntary and Community Sector.

10.7 There is no statutory obligation to fund respite care for adults

The Panel raised concerns that the States of Jersey does not have any statutory obligation to fund respite care. As a result, respite services could be an easy target for funding cuts, particularly in our current economic climate. We questioned the Health Minister on whether he had any plans to introduce a Social Services Law, which would include adult respite:

“No, we are not at the moment. [...] To answer your question specifically, was I intending to bring some sort of Social Services law, no, I was not. I would have to be convinced that

⁷⁷ Public Hearing with the Minister for Health and Social Services, 24th April 2015, page 11

⁷⁸ Public Hearing with the Minister for Health and Social Services, 24th April 2015, page 12

⁷⁹ Public Hearing with the Minister for Health and Social Services, 24th April 2015, page 13

would be very beneficial, but I do believe that we are undertaking complete reviews of everything that we are providing at the moment.”⁸⁰

In the UK adult social care used to fall within the statutory remit of the 152 Councils with Adult Social Services Responsibilities, an arrangement that dated back to the National Assistance Act 1948⁸¹.

The Law Commission published a report in 2011 which consulted on options for reform of the Adult Social Work system. The report made a number of recommendations for a single, clear, modern statute and code of practice that would create a coherent social care system. Under the reforms proposed in the report, older people, disabled people, those with mental health problems and carers would be clear about their legal rights to care and support services. Local councils across England and Wales would also have clear and concise rules to govern when they must provide services⁸².

The Care Act 2014 implements the Law Commission’s recommendations in England. The Act sets out a new legal framework for the provision of care and support services to older and disabled people, and their carers, plus safeguarding vulnerable adults from abuse and neglect. The Act came into force in April 2015⁸³.

In Jersey, there is a disparity between children’s and adult services for social Work. The 2002 Children’s Law establishes the legal framework for children’s social work, the fundamental purpose of which is to safeguard and promote the welfare of children⁸⁴. However, there is no statutory framework for the provision of social care for adults. Therefore, all engagement with social care services is undertaken on a voluntary basis. The only area where legislation applies to social work regarding adults is under the Mental Health (Jersey) Law 1969⁸⁵, which is currently being updated.

KEY FINDING 14: The States of Jersey does not have any statutory obligations to fund respite care for adults. As a result, services could be an easy target for funding cuts, particularly in the current economic climate.

RECOMMENDATION 8: The Minister for Health and Social Services should introduce a Social Services Law with regulations and guidance to accompany the law which include a requirement to provide a break for carers and for individuals with disabilities in order to improve the quality of their lives.

⁸⁰ Public Hearing with the Minister for Health and Social Services, 9th February 2015, pages 40 and 41

⁸¹ Health Committee – Third Report, Social Care, published 4th March 2010

⁸² The Law Commission, information sourced from www.lawcommission.justice.gov.uk

⁸³ The Law Commission, information sourced from www.lawcommission.justice.gov.uk

⁸⁴ Written question to the Minister for Health and Social Services by Deputy M. Higgins, 14th April 2015

⁸⁵ Written question to the Minister for Health and Social Services by Deputy M. Higgins, 14th April 2015

11. THE FUTURE OF RESPITE SERVICES

As we were reaching the end of our review, we were made aware of the work being undertaken by the Health Department in order to improve respite services for adults. A Commissioning Intentions Paper has been drafted which proposes a new direction for short break services. As this work is still in development and because we did not want to further delay publishing our report, we have made the following comments based on the information we have received so far. We are aware that further work needs to be carried out by the Health Department which may mean further Scrutiny work for us in the future.

11.1 Commissioning Intentions Paper: Whole System Redesign of Short Break Services

The paper explains that in 2014 the main provider of short breaks for young adults (Highlands Luxury residential Home) withdrew from the market which meant that temporary arrangements were put in place at Cheshire Homes. There has been a growing concern from parents of young adults regarding sustainability which is also influenced by choice and the increasing move from residential to flexible or outreach solutions. The paper also explains that the introduction of the Long-Term Care Scheme has the potential to further destabilise the adult short breaks market if service providers are unwilling to risk non-guaranteed income due to individuals commissioning their own services.

The Panel understand that no decision had been taken to transfer the adult short breaks budget to the long-term care fund.

Amongst other service proposals the following is being proposed which will affect adult short break services:

1. Employ a “care navigator” for a limited period of time to identify unmet need and help families make choices and access services.
2. Change the client group of one residential short break facility, to focus on the needs of young adults. This would reduce the number of beds available for children’s residential short breaks to 7 [from 11] and increase the number of beds available for young adult short breaks to 7 or 8 [from 4].
3. Introduce clear eligibility criteria for adult short breaks and monitor uptake, aiming to increase access and reduce unmet demand.

We would like to make the following comments on the service proposals detailed above.

1. Employing a “care navigator”

It is understood that this individual’s role will be to work with carers to identify unmet needs, and to help carers navigate services and choose the most appropriate respite to meet all of their needs. It is unclear whether this post will be held within children or adult services, but our evidence suggests that this kind of navigation support needs to be given to carers in both areas and not just for a short period⁸⁶.

⁸⁶ Evidence taken from the previous Panel’s review of Respite Care for Children and Young Adults (S.R.2/2012)

RECOMMENDATION 9: A “Care Navigator” will be employed for a short period by the Health and Social Services Department to work with carers to identify unmet needs and choose the most appropriate respite to meet all of their needs. The Panel’s evidence suggests that support for carers in both the children’s and adult services is required and not just for a short period.

2. Changing the client group of one residential short break facility

The Department’s plans include changing Maison Allo, currently a respite home for children with mild to moderate learning disabilities, into a residential overnight facility for young people aged 14 - 21. Maison Allo is owned by Jersey Mencap and run by Les Amis.

The Panel has been made aware of the concerns from families currently accessing Maison Allo. In a written submission to the Panel from the Special Needs Advisory Panel (SNAP), which can be viewed in full in appendix 1, we have been informed that families currently accessing the service will not lose their overnight short break, however, depending on their child’s age they will be contacted by children’s services within the next few weeks to make plans to move their child to another provision. There have been concerns expressed by parents that this will not be a simple exercise to move their child to a new provision, as some children have taken months, even years to settle into new environments.

The Panel shares SNAP’s fears that this proposal is a quick-fix solution to insufficient respite provision within adult services. This will reduce respite capacity for children and the options available to parents. The Panel seeks firm evidence from the Minister that the proposals put forward will not reduce provision in the children’s respite service.

SNAP asks for the following to be addressed and explored in more detail:

- Agreement and full backing from Jersey Mencap to allow Maison Allo to be repurposed as a Young Persons Residential Provision.
- Evidence to show using Maison Allo is the best and most viable option compared to providing a bespoke Young Adults provision with Andium Homes or even one of the States of Jersey’s existing properties.
- Assurance that Maison Allo is the correct facility to meet all the needs of these young people. Currently there is only one ground floor bedroom with no hoist and only a ground floor toilet which is not appropriate for those young people in wheelchairs. It is important to look at all individuals who may require nursing care due to their complex health needs. Will they all be able to be accommodated within this provision?
- Plans are in place to convert the garage at Maison Allo into a wet room. What are the costs for refurbishing Maison Allo to meet all the specifications required for wheelchair access?
- Before plans are implemented and bed space is reduced an exercise needs to be carried out as soon as possible to assess families within Children’s Services to see if they are happy with their current level of respite service and whether they need more support.

- Health and Social Services need to confirm how they came to the conclusion that Jersey currently has too many bed spaces per our population within Children Services for overnight short breaks. Is this a comparison used in the UK or do they have accurate data to prove this is the case in Jersey?
- If Maison Allo is repurposed then evidence needs to be provided to show that Eden House and Oakwell have sufficient capacity to meet the needs of families now and in the future.
- A guarantee that if there is insufficient capacity within Children Services due to repurposing Maison Allo then the Minister will explore options to ensure these needs are met.
- An Emergency Provision is provided for families who go into crisis which is separate from the facilities and staff from Eden House and Oakwell.
- Essential pieces of work are completed as soon as possible to implement the new Pathway of Services in its entirety and a realistic timeframe of when this will be fully operational for families to access.
- The Eligibility Criteria to receive an overnight short break is fair and will not be so tight that it will only be available to a select few.
- Have families with Young Adults and the Young Adults themselves been told of these plans and are they supportive of the change of purpose at Maison Allo.

The Panel met with the Managing Director of Les Amis on the 26th June 2015. He explained that a proportion of the required funding had been granted by the Association of Jersey Charities which could be used to repurpose the garage into a disabled access bedroom and wet room. He also advised us that building works would not commence until firm plans were in place for a change in the service. If plans were approved, the work could be completed within 8 – 12 weeks.

KEY FINDING 15: The Health and Social Services Department has proposed repurposing Maison Allo, currently a respite home which sits within the children’s service, to a young person’s facility for ages 14 - 21. Not only might this disadvantage children aged under 14, it also fails to address the residential based respite needs for adults aged over 21.

RECOMMENDATION 10: In order to ensure repurposing Maison Allo is the right approach, the issues identified by the Special Needs Advisory Panel (SNAP) should be fully addressed and answered in writing before plans for the facility are implemented. This formal response to SNAP’s concerns should also be circulated to all service users of Maison Allo.

3. Introducing eligibility criteria for accessing short break (respite) services

Access to short breaks is determined by a professional assessment of need. Currently within adult services there are no formal eligibility criteria for access to short breaks for adults and older adults. Their needs are determined by professional opinion based on an assessment from a social worker, supported by a specialist assessment by a community nurse or therapist dependent upon the complexity of need⁸⁷.

⁸⁷ Commissioning Intentions Paper: Whole System Redesign of Short Breaks Services

The Health Department is now looking at introducing eligibility criteria for adult respite services. Although the criteria could ensure a transparent and consistent approach to allocating services to meet those in greatest need, the Department must ensure they are fair and not open to misinterpretation. The Panel believe that fairer access should not mean that fewer families receive residential respite care.

KEY FINDING 16: The Health and Social Services Department plan to introduce eligibility criteria for those wanting to access adult respite services. Although eligibility criteria could ensure a transparent and consistent approach to allocating services, it should not mean that fewer families receive residential respite care as the Panel considers residential based respite care to be a crucial component in the service offered to families.

RECOMMENDATION 11: The Health and Social Services Department should ensure that the eligibility criteria for accessing adult respite services are fair and consistent. Before finalising the criteria, the Health and Social Services Department should consult fully with the Special Needs Advisory Panel and other stakeholders..

12. CONCLUSION

The Panel conclude that there is not sufficient respite provision for adults in Jersey and not enough has been done to improve the service.

The development of home based respite services in recent years in addition to residential based respite care means that people can have tailored and appropriate care in response to their needs. However the Panel believes that these types of respite services should be an additional option for families rather than a replacement for residential respite services.

The Social Security Department has allocated respite for up to 6 weeks annually for those who qualify for the Long-Term Care Scheme depending on how much informal care is provided. The Panel is concerned that there may not be sufficient overnight residential based respite provision provided by the Health Department to allow for this much respite care. Therefore, families may have no other choice but to access home based respite care, which some feel is inappropriate for their needs.

The Panel has found that choice is a key factor in providing respite provision. There is no one size fits all service and people need breaks in different ways, at different times and for different periods.

The Panel has found that there is a disparity between the numbers of beds available within the children's service compared to the adult service. Not only are there a lot more rooms which provide for wheelchair users, hydrotherapies are available on site at one of the respite homes. The expectations, therefore, may be disappointing for some service users and their carers when entering adult services. It is clear the levels of service should be maintained within the adult service.

The Panel find it unacceptable that a proposal to develop a bespoke adult respite home fell away without any satisfactory explanation. The Panel found no audit trail to explain the reasons why the plans had been progressed to almost the point of delivery and then suddenly halted. This was particularly disappointing as Panel's evidence shows that there is and will continue to be a strong demand for residential based respite care in Jersey.

The Health and Social Services Department is already working up plans to address the lack of respite provision for adults by repurposing a children's respite facility into a respite home for young people aged 14 – 21. Not only might this disadvantage children aged under 14, it also fails to address the residential respite needs for adults aged over 21. The Health and Social Services Department must provide evidence that such a proposal will not have a negative impact on those who fall outside of the age bracket.

A sustainable and reliable respite service is important in order to help prevent families reaching crisis point due to the stress of full-time caring. These carers make a vital contribution to the lives of people with disabilities, often providing most of the support they need. Additional expenditure now on respite services is likely to mean lower expenditure in the future on addressing the negative consequences of insufficient respite for carers.

13. APPENDIX 1: SUBMISSION FROM SPECIAL NEEDS ADVISORY PANEL



24 June 2015

Dear States Members

We are writing on behalf of the Special Needs Advisory Panel (SNAP) with regard to the plans by Health & Social Services to repurpose Maison Allo to provide a residential overnight provision for Young People 14 years +.

As you are aware Maison Allo is owned by Jersey Mencap and Les Amis currently run the service to provide overnight short breaks for families of children between the ages of 5 years until they reach 18 years old when they then transfer into Adult Services.

A parent from Mont á L'Abbé School whose son attends Maison Allo, and who fully appreciates the service they provide to her family and more importantly the benefits that her son gains from his weekly overnight respite break was appalled to find out that Maison Allo was closing its doors twice a week and was running at half capacity.

She knows many families who need this vital break and asked why Maison Allo was in this position. She was told that Les Amis have not had a referral for over 26 months from Children Services to provide an overnight short break even though Les Amis have been fully funded to provide this service to families.

When she enquired with Children Services she was told that they had no families waiting or needing an overnight short break and that everyone was happy with their new Community Short Break.

Knowing that there were many families who needed an overnight short break she arranged for families to meet Jo Olsson, Interim Director of Children Services and her colleagues at Mont á L'Abbé School on 18th May 2015. SNAP were asked to attend this meeting and this is why we are involved.

Unfortunately, Jo and her colleagues were not able to talk about any provisions that offer overnight short breaks or any individual cases. Parents were only told that they had plans to implement a new Pathway of Services which will be tiered into four categories 1) Universal, 2) Community Short Breaks & Short Breaks +, 3) Complex Care Packages and 4) Alternative to Community Based Care but they were told very little detail and how this would affect them.

After this meeting parents were left frustrated that they had so many unanswered questions and they felt very suspicious that plans were being made behind closed doors which could possibly affect them and they were very disappointed that no one was being honest.

Parents decided they needed to raise their concerns and wanted answers to their questions and arranged a meeting with the Minister for Health & Social Services, Senator Andrew Green on 15th June 2015.

Senator Green attended this meeting with Jo Olsson and her team at Mont á L'Abbé School and the turnout from worried parents, carers and professionals showed in numbers that they were all very concerned.

At the meeting we were all informed that Maison Allo would become a residential provision for young people so they can stay within Maison Allo to ensure a smooth transition into Adult Services.

Families who are currently using Maison Allo were notified that they would not be losing their overnight short break however depending on their child's age they will be contacted by Children Services within the next few weeks to make plans to move their child to another provision.

These families are very concerned that it is not a simple exercise just to move their child to a new provision as some children have taken months, even years to settle into new environments.

There was no mention of plans for families whose young adults have only just recently moved into Adult Services and for those who have been using Mourant Lodge for some time however, some families have raised their concerns that they will also have difficulty moving their child back to Maison Allo if this is the case.

Senator Green explained to the group that their children will grow up and currently they have a shortage to provide this essential service to this group of young people.

No one could explain why the States of Jersey have allowed this situation to reach crisis point when this has not happened overnight and Adult Services have been aware of this problem for many years.

Due to the urgency of Adult Services only having one bed at Mourant Lodge at the beginning of August, families feel that Health & Social Services are looking for a quick fix solution and utilising Maison Allo is their answer. Families feel that they have not been given enough evidence to show that this is the right decision.

Everyone agreed with Senator Green that their children will grow up and that this provision is needed but why take away a provision that is currently used for children when there are families who need this service now and why not look at providing a purpose built provision that will cater for all the needs of these young people. One parent asked why are you paying Peter to rob Paul?

Parents expressed their views and concerns to the Minister about the proposed changes as they are very worried that if Maison Allo is repurposed and that 28 bed spaces are lost, what will be the impact on the remaining 2 provisions Eden House and Oakwell.

The Senator confirmed that they believe Eden House and Oakwell have enough capacity to provide overnight short breaks. When asked if he had sufficient data / information about the number of families in the system and what their needs are now and in the future, he did not think they had this data. He did confirm that if after their plans there is insufficient capacity to meet the needs of families that he would explore options to ensure this need is met. This statement has not convinced families that Health & Social Services have done their research and that hasty decisions are being made without supporting evidence.

Jo Olsson confirmed that her department have done some work on data but no work has been carried out to ensure current families are happy with their Community Short Break and if they need more support etc.

Families who currently need respite are being offered a Community Short Break if they meet the set criteria and this is the 2nd level of service on the new Pathway of Services.

Community Short Breaks was launched in November 2014 and the standard offering for a Community Short Break is 3 hours per week with 6 hours in the holidays. As this is a new service families feel that it has been pushed on to them and do not feel 3 hours a week is sufficiently meeting their needs.

Families agreed that this service is beneficial especially for younger children but it is not enough for families with older children. Some families have told us they had accepted the 3 hours as they feel it is better than nothing which seems a totally waste of money and resource.

Some families have only been offered their 3 hours after school which means they do not have much time or even opportunity to enjoy activities with their other family members as their children have just come out of school and their partners are at work.

The Community Short Break should allow families a suitable break, have time to spend with their other children and an opportunity to enjoy what our beautiful island can offer which they cannot do when looking after their complex needs child.

As part of the Universal and Community Short Break offerings we were advised that Children Services are currently looking to provide a more varied menu of services to give children an opportunity to be involved in activities already provided across the island.

There is also a Community Short Break + which needs to be implemented but we are not aware what this offering is and when this will be available to families.

The Community Short Break service is new and of course it has had its teething problems as not all the service providers can offer families the flexibility and also essential bases that some children with higher complex needs require.

Families feel that Children Services need to review this service with families now to ensure they are getting the support they need and more importantly it is benefiting their child before they start taking away essential bed space/provision.

Families who have requested more support in the way of an overnight short break have been told by Children Services that it is a very daunting experience for their child and they have been made to feel very guilty for asking. Some families have even been told there isn't any bed space available.

Parents are also being told that to receive an overnight short break they will need a Social Worker. They are being advised that their child will be known within Social Services as a "looked after child" in Jersey and this will mean that the Social Worker will have a lot of involvement and say in their child's care. This is scaremongering and has put families off requesting for an 'assessment of need' to get an overnight break for their child.

Families really feel that Children Services have done their best to put them off getting an overnight short break and believe that they are not referring families to ensure their plans for Maison Allo go ahead. This was refuted by Jo Olsson at the meeting.

The Health, Social Security & Housing Scrutiny Panel's report on Children's Respite Service back in 26th April 2012 highlighted that Jersey only has 3 small provisions (Maison Allo, Eden House & Oakwell) to offer this essential service to a population of 100,000 people and the demand for respite is rising.

Jo Olsson confirmed that Jersey actually has too many bed spaces per our population which contradicts Scrutiny's findings. We can confirm that Mont á L'Abbé School will have their biggest intake of children of all ages this September and these families could potentially need respite.

More importantly from this report Health & Social Services have still not provided an Emergency Care provision and this was a top priority recommendation as emergency residential cases evidently have a huge impact on other families respite.

To date we can confirm that Eden House is still being used for emergency cases and is currently supporting a family in crisis. This has resulted in a staff shortage to provide Community Short Breaks and bed space being offered to families at this provision.

As you are aware an overnight break is a vital service to a family looking after a child with complex needs but it is more importantly beneficial for the child especially as they learn life skills, new rules, they can socialise with their friends, have a break from home, learn to be in new environment, and it prepares them for their future etc.

Parents cannot provide these benefits for their child at home and also do not have regular opportunities to have a complete break themselves to recharge their batteries, sleep, spend time with their other children, family, friends etc so this service is so important to enable parents to continue to care for their child at home and also have a good life balance.

As an overnight short break is under the 'Complex Care Packages' step 3 on the new Pathway of Services, parents viewed their concerns that the Eligibility Criteria to receive an overnight short break will be made so tight that it won't be available to all families in the future hence why Children Services are confident that Eden House and Oakwell will have sufficient capacity.

Jo Olsson confirmed that the Eligibility Criteria and the Referral Process to request a Social Work 'Assessment of Needs' for an overnight short break has not been compiled yet and she invited a group of parents and SNAP to be involved in this work which we feel is a very positive move.

It is however, very worrying that key pieces of work are still in the planning process and have not been completed to ensure the new Pathway of Services is implemented to its full potential whilst in the meantime vital decisions are being made to reduce capacity within Children Services.

It is apparent that there is still a lot of work to be done in order for the new Pathway Service to be up and running and we are not aware of the timeframes for when this will be fully operational.

During the meeting Carol Canavan who is the Chair of Jersey Mencap announced to the Minister that Jersey Mencap who owns Maison Allo has not been approached to discuss and agree these plans by Health & Social Services. The audience were left astounded that Health & Social Services have made all these plans without consulting the landlord of the building and they were going ahead in a few weeks with plans to start moving families out of Maison Allo.

Carol and the Minister agreed that an urgent meeting outside of this meeting was required as Carol confirmed that she would need to bring this proposal to her Committee, they would require appropriate figures / data before an agreement could be made and if they did agree then she would need to bring this to an AGM.

There seems to be a lot of unanswered questions and the following needs to be addressed and explored in more detail before families will fully support this move.

- Agreement and full backing from Jersey Mencap to allow Maison Allo to be repurposed as a Young Persons Residential Provision.

- Evidence to show using Maison Allo is the best and most viable option compared to providing a bespoke Young Adults provision with Andium Homes or even one of the States of Jersey's existing properties.
- Assurance that Maison Allo is the correct facility to meet all the needs of these young people. Currently there is only one ground floor bedroom with no hoist and only a ground floor toilet which is not appropriate for those young people in wheelchairs. It is important to look at all individuals who may require nursing care due to their complex health needs. Will they all be able to be accommodated within this provision?
- Plans are in place to convert the garage at Maison Allo into a wet room. What are the costs for refurbishing Maison Allo to meet all the specifications required for wheelchair access?
- Before plans are implemented and bed space is reduced an exercise needs to be carried out as soon as possible to assess families within Children Services to see if they are happy with their current level of respite service and whether they need more support.
- Health & Social Services need to confirm how they came to the conclusion that Jersey currently has a too many bed spaces per our population within Children Services for overnight short breaks. Is this a comparison used in the UK or do they have accurate data to prove this is the case in Jersey?
- If Maison Allo is repurposed then evidence needs to be provided to show that Eden House & Oakwell have sufficient capacity to meet the needs of families now and in the future.
- A guarantee from Senator Green that if there is insufficient capacity within Children Services due to repurposing Maison Allo then whoever is the sitting Minister for Health & Social Services will explore options to ensure these needs are met.
- An Emergency Provision is provided for families who go into crisis which is separate from the facilities and staff from Eden House and Oakwell.
- Essential pieces of work are completed as soon as possible to implement the new Pathway of Services in its entirety and a realistic timeframe of when this will be fully operational for families to access.
- The Eligibility Criteria to receive an overnight short break is fair and will not be so tight that it will only be available to a select few.
- Have families with Young Adults and the Young Adults themselves been told of these plans and are they supportive of the change of purpose at Maison Allo.

SNAP fully appreciates that the situation Adult Services find themselves in is totally unacceptable and this urgently needs to be addressed.

We just want to ensure that by changing Maison Allo's remit and reducing the number of beds available within Children Services is the right approach and it is not just a quick fix.

We do not want to find that our families in the future will be turned away for essential overnight respite as Eden House and Oakwell are full to their capacity.

Please can you take into consideration all of the above especially the concerns and feelings of the families we support.

Lesley Bratch, Chair of SNAP

Lisa Jacobs, SNAP Representative for families of Mont á L'Abbé School

contact@snapjersey.co.uk

14. APPENDIX 2

14.1 Panel Membership

Deputy Richard Renouf, Chairman
Deputy Geoff Southern, Vice-Chairman
Deputy Terry McDonald
Deputy Jackie Hilton, Co-opted Member

14.2 Terms of Reference

1. To assess the current provision of respite services for adults and determine their effectiveness with particular reference to:
 - a) Short-term stay;
 - b) Long-term stay; and
 - c) Day Services
2. To assess whether respite services for adults are fit for purpose with particular reference to:
 - a) Estate/property;
 - b) Manpower Resources; and
 - c) Funding
3. To determine whether adequate support is in place for respite users who are transitioning in and out of Adult Services.
4. To assess the opportunities and support available for adults with special needs in Jersey regarding training and employment.
5. To examine the relationship between Voluntary and Community Sector organisations and the States of Jersey with particular reference to Service Level Agreements.
6. To examine the terms and conditions of service of support workers providing respite care.
7. To determine the training currently available for respite service providers and the retention rate of staff.
8. To assess Ministerial responsibilities for the provision of adult respite care.

14.3 Evidence Considered

Public Hearings

- Minister for Health and Social Services: 9th February 2015
- Executive Officer of the Jersey Employment Trust: 16th March 2015
- Assistant Chief Minister and Chairman of the Service User Forum

Assistant Director of Social Policy, Chief Minister's Department: 20th March 2015

- Minister for Social Security: 21st April 2015
- Minister for Health and Social Services: 24th April 2015

Private Hearings

- Witness 1: 16th February 2015
- Witness 2: 16th February 2015
- Witness 3: 20th February 2015
- Witness 4: 20th February 2015

Written submissions

Following the public call for evidence, the Panel received a number of written submissions from families and carers.

Panel Visits

The Panel made the following evidence-gathering visits:

- **6th February 2015**

Mourant Lodge – Les Amis
Le Geyt Centre

- **11th February 2015**

Jersey Cheshire Homes

- **4th March 2015**

Eagle House – Community and Social Services

- **6th March 2015**

Mont à L'Abbé Secondary School

- **20th April 2015**

The Panel received a PowerPoint presentation by carers/parents on the future of respite at Le Geyt Centre