



Health, Social Security and Housing Scrutiny Panel

Respite Care for Children and Young Adults Review



Presented to the States on 26th April 2012

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CHAIRMAN'S FOREWORD

Children with complex and/or challenging needs are amongst the most vulnerable in our society, as many are unable to communicate and some have limited mobility.

When setting out its vision, outcomes and principles in the Children and Young Person's Framework last year, the Department of Health and Social Services, which leads the Children's Policy Group, states amongst its five principles "*we will 'think family' – supporting families is critical to supporting children.*"

The Health, Social Security and Housing Scrutiny Panel has been saddened to discover that the support offered by the Department has been failing to provide continuity of service to vulnerable families within our community.

This report illustrates why it is essential that the Department offers guaranteed respite to families as well as to make the service available to a greater number.

The Panel met with many families who are currently caring full time for a child or young adult with special needs. These families are devoted to caring for their children, but whilst the majority of parents have ready access to short breaks from their caring role (in the form of a wide range of free and fee-paying services to care for and entertain their children) on a regular basis, those caring for children with special needs struggle to find that crucial time out for themselves or the child's siblings. In some cases, even extended family members are not able to cope with the specific needs of the children.

By providing a reliable respite service, the Department would not only give parents the support that they need to cope with their weekly routine, they would also help children to develop independent living skills. This, combined with improved Adult Services, will help to ease one of the biggest concerns we heard from parents, which was the deep-seated worry they carry regarding their child's future once they approach old age. Enhancing these services would help to alleviate some of that burden.

Jersey is fortunate to have a great number of skilled and committed care workers. We would like to pay tribute to all frontline staff and it is the Panel's hope that their working environment will be improved as a result of this report.

A number of parents have expressed their gratitude to the Panel for offering them a listening ear through the Scrutiny process. It is the Panel's intention that this review will bring some positive improvements to the lives of these devoted families, not just a cathartic process.

The Panel would like to thank the witnesses who came forward and told their stories, as well as the Department for answering our many questions and providing a great deal of information for us.

The situation we find ourselves reporting on today is symptomatic of a lack of political direction, leadership and investment from the Department over the past two decades. This Panel has the distinct impression that there is now a will to tackle issues that have been left to fester. We feel confident that our recommendations will be well received, there are many, but we feel they are both realistic and achievable. Most importantly the families of Jersey deserve nothing less.

This work could not have been done without the advice and guidance of our advisor, Siôn Jones, to whom we are very grateful, and the two sterling Scrutiny Officers, Kellie Boydens and Fiona Carnegie, who have grasped the issues at hand and worked diligently and with great purpose to publish this report.



Deputy Kristina Moore
Chairman, Health, Social Security and Housing Scrutiny Panel

TERMS OF REFERENCE

Review of Respite Care for Children and Young Adults

- To assess what respite services are available to support families who have children and young adults with special needs such as complex health needs, "challenging" behaviour and autistic spectrum disorders.
- To assess whether the respite services available are fit for purpose and whether they can meet future needs.
- To determine what agencies are involved and what resources are available with particular reference to:
 - Financial resources including government funding
 - Property
 - Manpower
- To assess what involvement third sector organisations have in the delivery of respite services and how these are funded.
- To examine what criteria is used to determine access to respite services and the level of care provided.
- To assess how the short and long term needs of the users are determined, and how these needs are provided for.
- To examine the transitional period from children's service to adult service, with particular reference to:
 - Resources available;
 - How the transitional period is managed;
 - Any variation to the level of respite care provided.
- To determine whether the States has responded to recommendations of previous reviews and enquiries into respite care for children and young adults.
- To examine any further issues relating to the topic that may arise in the course of the Scrutiny review that the Panel considers relevant.

PANEL MEMBERSHIP

The Health, Social Security and Housing Panel comprised the following Members:

Deputy Kristina Moore, Chairman

Deputy Jacqueline Hilton, Vice-Chairman

Deputy James Reed

Expert Advisor

The Panel appointed the following expert advisor:

Mr Siôn Jones

Siôn Jones is a Partner at LE Wales, an economic and policy consultancy, and has over twenty years experience as an economist and policy advisor. He leads their Health and Social Care team and has undertaken research on respite care services in Wales as well as in other care-related areas such as foster care services, non-residential care services, housing support services and disability benefits.

EXECUTIVE SUMMARY

Respite care is designed to provide a break for carers and families as well as offering an important opportunity for children and young adults with a learning or physical disability to socialise with friends and learn new skills. Respite care also gives other family members the chance to spend quality time together. The Health, Social Security and Housing Panel decided to review the respite care service in Jersey after being contacted by a member of the public in September 2011. The individual told the Panel that the respite service was under strain due to emergency care cases taking up resources at respite homes, and that some families were suffering as a result of their respite care being withdrawn or reduced. Written submissions from members of the public who were accessing respite care confirmed that there are significant problems with the way the current system operates.

Jersey has no statutory duty of care to provide respite care for children and young adults with special needs, nor a clear social policy that enshrines the rights of the most vulnerable in society. This is in contrast with almost every other UK jurisdiction, as well as the Isle of Man. Currently only three residential respite care homes exist to cater to the needs of nearly 100,000 people. Oakwell Children's Respite Centre offers short breaks and support to children and young adults with severe mobility problems or profound and multiple learning difficulties. Eden House provides short breaks and support to children and young adults with Autistic Spectrum Disorders. Both Oakwell and Eden House are funded and run by Health and Social Services. Maison Allo offers short breaks to children with mild to moderate learning disabilities. This service is run by Les Amis on behalf of Jersey Mencap and funded by a grant from Health and Social Services. The third sector makes a valuable and significant contribution to both the funding and provision of respite care services. The Panel urges the Department to strengthen existing partnerships with the third sector to improve the range of respite services.

The demand for respite care in Jersey is rising. This is partially due to the growth in the population and also a result of improved medical interventions at birth, which are increasing the survival rate for severely disabled children. However, the Panel found that the current respite care provision does not adequately meet the needs of the community at present. There also appears to be a disparity between the volume of demand expressed by families and the perception of demand held by Health and Social Services. Given that there is no official record of the number of people in Jersey with a life-long disability, demand for respite care is only planned for and delivered on the basis of the most visible need. The Panel feels that this approach does not cater to the growing needs of the Island's community either now or in the future.

The Panel identified that the lack of dedicated emergency care facilities for children with emotional and behavioural disorders has led to Eden House being used to accommodate young adults with an Autistic Spectrum Condition who had experienced a stress-related family breakdown. This has meant that at certain times the service has been shut down to regular users with little notice, causing significant distress and stress to other families denied a break from full-time care. Furthermore, the Panel learned that the respite care service was failing to adequately support parents of school age children at weekends and during school holidays, with a lack of outreach services creating an inconsistent care burden for parents outside of term time. The support offered by the current respite service also falters at the transition between Children's Services and Adult Services, and many parents are highly anxious about the prospects for their children once they had left the stimulating environment of school and children's respite.

Accessing respite care depends on referral from a healthcare or education professional followed an assessment of need. At present, two dedicated social workers manage the caseloads of every child with special needs who may require respite care. Many parents felt that accessing respite services was overly difficult and time-consuming, with many highlighting that going through Social Services can be an intimidating process without the support of an advocacy worker. The Panel learned that there are a number of factors that limit the accessibility of respite care. As a priority, the Panel feel that more frontline staff must be appointed to help meet the needs of the community

and guide them through the assessment process for respite care. Further, the Panel feels that more information about the range of respite services and how to access them is urgently required.

Whilst many parents are happy with the quality of care their children receive at respite homes, some of the facilities require urgent updating to meet current minimum standards for Children's Care Homes. The Panel urges the Department to prioritise the improvement of facilities for children's respite care, as well as to identify proper locations for the provision of emergency care and long-term care for children and young adults with severe emotional and behavioural difficulties.

Following this review, it is clear that improvements to the service must be made. The Panel looks to the Minister to implement the necessary changes to make Jersey's respite care service an example of best practice of how a small community can care for its most vulnerable.

KEY FINDINGS

1. The lack of regular, sustainable respite care services for the majority of the user group is unachievable based on the current system. The Panel believes that a significant number of families who would benefit from respite care are not receiving it because of a poorly managed approach to assessing demand. A sustainable and reliable respite care service is important to help prevent families reaching crisis point due to the stress of full-time caring. **[Section 3.1]**
2. The failure on the part of Social Services to proactively identify and support those families in greatest need before they reached breaking point ultimately precipitated two separate family breakdowns and significant disruption to the rest of the respite care service. **[Section 3.2]**
3. There is no comprehensive data on the number of children and young people with disabilities in Jersey or the nature of their disability. This makes assessing current and future demand almost impossible. **[Section 3.3]**
4. There are only three small residential respite homes offering respite care specifically for children with special needs: Oakwell, Eden House and Maison Allo. Furthermore, there are two sites offering respite care services to adults. **[Section 4.8]**
5. Outreach for children is delivered from the same resources as that allocated to residential respite, which restricts available outreach during busy periods. **[Section 4.8]**
6. The third sector makes a valuable contribution to funding and supporting respite care in Jersey. Social Services and the third sector would benefit from improving their lines of communication. **[Section 4.11]**
7. The Panel identified three main circumstances in which the current supply of respite care is failing to meet the needs of the community; during emergency and crisis situations, during the transition phase to adulthood, and during school holidays and after school. **[Section 4.16]**
8. Emergency care is currently provided within the two States-run respite homes. This has meant that when a respite home is being used for emergency care, other families who would have normally been provided for were not able to access essential and short-term respite. **[Section 4.17]**
9. The lack of long-term care facilities for children with complex needs means that respite homes have been used for this purpose, to the detriment of other residents. **[Section 4.18]**
10. Families face significant challenges when their child reaches the age of 18 and moves from Children's to Adult Services, especially as the system does not provide for a personal care plan or individualised budget. Instead, access to necessary support services depend on the resources available within the Adult Services budget at the time. **[Section 4.19]**
11. Once young people leave full-time education the range of available respite type services changes dramatically. Furthermore opportunities available for young adults with special needs in Jersey in terms of access to training, employment or day services are limited. **[Section 4.21]**
12. At the end of full-time education the personal commitment required from the carer increases dramatically. As a result some have to give up work which affects their ability to deal with the day to day financial matters that many of us take for granted. **[Section 4.22]**

13. The Department's perceptions of the transition service are unrealistic. The current transition system does not work properly, reflecting problems with the delivery of transition support by two separate services. **[Section 4.23]**
14. Children with special needs are at a distinct disadvantage compared with their able bodied peers in terms of choice of holiday and after-school activities. This places an additional burden on the carer, who is trying to balance work and family life with the needs of their child. **[Section 4.24]**
15. The States do not have a duty of care to provide respite care for families in Jersey, nor a clear social policy that enshrines the rights of the most vulnerable in society. This is in contrast with almost every other UK jurisdiction, as well as the Isle of Man. **[Section 5.1]**
16. There is a need for a more coherent, joined-up approach to assessment to address the holistic needs of the child and the family. Eligibility for respite care is dependent on someone being referred by a GP or by contacting the Special needs service directly. Following a referral to the Special Needs team an Assessment of Need should be produced by the Social worker assigned to the case. The Department is looking to pilot the Common Assessment Framework as Jersey has not yet reached the point where all parties contribute to one singular assessment. **[Section 5.5]**
17. The referral process for respite care can be intimidating for some parents, and without the support of an advocacy worker some families may never be able to access the necessary support. **[Section 5.7]**
18. Some professionals working with children with autism are concerned that clients are not receiving diagnosis early enough or, in some cases at all because of a squeeze on resources available for this client group. This also impairs the ability of the service to respond to new instances of need as they arise. **[Section 5.8]**
19. There is no evidence of formal criteria to assess a family's need for respite care, nor a written down Departmental policy with regard to how respite care should be accessed and delivered. Eligibility for respite is currently assessed through professional judgement and the severity of the family situation, which in times of respite shortage has meant that families are forced to breaking point to access services. **[Section 5.9]**
20. Information about what respite services are available and how to access them is minimal, hard to find and poorly signposted by professionals. The Panel was told that the Department seeks to avoid unnecessary intrusion into people's lives. However, this approach was felt to be a barrier to some families gaining access to services at an earlier stage. **[Section 5.10]**
21. Social Workers currently assigned to work with families of children with special needs are held in very high regard. However, there is a lack of Social Workers available to support those parents of children with special needs. **[Section 5.11]**
22. Whilst Oakwell is currently providing a good service in terms of quality of care, the Panel is concerned that the physical environment fails to meet modern day standards. **[Section 6.1]**
23. The Panel was advised that when Eden House was constructed in 2004, it would not have passed UK inspection according to the minimum criteria laid down for Children's Homes that relate specifically to health and safety criteria for children with Autistic Spectrum Disorders and emotional and behavioural difficulties. The current refurbishment aims to address these key issues. However, the building is only suitable for primary-school aged children, not the adolescent group that is currently using it. **[Section 6.2]**

24. There are less adult respite facilities compared to children's facilities, and those that exist sometimes compromise the wellbeing of the client to cope with the existing provision. **[Section 6.3]**

25. Parents highlighted the importance of continuity in terms of staff caring for their children. The Panel recognises the importance of having appropriately trained staff to care for children and young people with special needs in any setting – public or private. **[Section 7.2]**

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. Demand is properly assessed by undertaking research aimed at identifying all families who would benefit from respite care. **[Section 3.1]**
2. That the Department adopts a more proactive approach to assessing demand and develops a range of early intervention programmes to avoid families reaching crisis point. This would prevent disruption to the respite service and to other families receiving regular respite. **[Section 3.2]**
3. An information management system is developed to capture the needs of the island's families who care for children with special needs. This data is captured from existing sources of knowledge (i.e. healthcare and education professionals). Consideration is given to using the next Social Survey to gather comprehensive information about individuals with special needs. **[Section 3.3]**
4. Residential and other respite services, including outreach, for both children and adults are fit for purpose and able to cater to both current and future demand. **[Section 4.8]**
5. A formal partnership is entered into with the main third sector organisations in order to deliver the necessary improvements to the range of respite services available to users. **[Section 4.11]**
6. The Community and Social Services Department is properly resourced and staffed accordingly to meet both current and future demand. **[Section 4.16]**
7. Emergency care facilities are identified as soon as possible to reduce the strain on respite care homes. This is especially important for young people with autism who are more likely to become difficult to manage in the home during adolescence. **[Section 4.17]**
8. Plans are prioritised for alternative sites for long-term care, and are in place as soon as possible. Any provision to take into account an expansion of demand and be able to cater for multiple crisis scenarios occurring at any one time. **[Section 4.18]**
9. 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. Ultimately, all children with special needs to have a personal care plan and individualised wraparound budgets that follow them throughout their lives to ensure the transition period is as seamless as possible. **[Section 4.19]**
10. Close working with other government and third sector organisations is undertaken to further develop the range of services available for young adults with special needs. Good relationships with local employers are fostered to ensure that there are opportunities for young adults with special needs to make a contribution to society. **[Section 4.21]**
11. The parent's ability to work and care for their family is supported as much as possible and resources for adult respite care and outreach are increased where appropriate. **[Section 4.22]**
12. A standalone 'Transition Team' is established to help parents and children navigate the difficult journey from Children's to Adult Services. **[Section 4.23]**

13. Where a childcare ratio is 2:1 or above within the school or respite facility, support is tailored to reflect that additional need in the home environment. **[Section 4.24]**
14. Resources are identified to fund more holiday club provision, in conjunction with the third sector and Mont à l'Abbé School. **[Section 4.24]**
15. Community care legislation is brought in to safeguard the rights of vulnerable children and young adults with regard to respite and other support services. **[Section 5.1]**
16. A Common Assessment Framework is introduced to make assessment quicker and easier to understand, and to ensure that all relevant parties are involved at each stage. The Record of Need is strengthened to ensure the overall needs of the child are met, as well as the educational needs. **[Section 5.5]**
17. Community and Social Services are re-named Community Services as part of a wider programme of communication about services available to members of the community. **[Section 5.7]**
18. Advocacy services are established to help parents navigate the referral process and to access respite. **[Section 5.7]**
19. The current criteria for diagnosing children with autism are clarified. The financial consequences are not the determining factor when deciding the level of respite required by a diagnosis. Resources are increased to allow respite providers to respond to new clients as appropriate. **[Section 5.8]**
20. There is: a) a formal policy outlining their approach to respite care and b) a set of detailed guidelines for professional 'gatekeepers' charged with assessment and referral. **[Section 5.9]**
21. A communications strategy is developed to outline all the respite support services available to parents and how to access them. This information is to be made freely available to all families caring for children with special need, as well as being uploaded to the Gov.je website and disseminated to all health professionals, educational establishments and parent support groups. **[Section 5.10]**
22. At least 1 x additional full-time Social Worker post assigned specifically to children with special needs is created. Equally, additional Support Worker posts for this user group are created to relieve the burden on Social Workers' workloads. **[Section 5.11]**
23. The future of Oakwell is decided in terms of refurbishing the current site, or constructing a new purpose-built facility in an alternative location in conjunction with the third sector. Any plans should take into account the rising demand for respite care. **[Section 6.1]**
24. Future residential developments for any group with special needs must take into account minimum environmental standards in the early planning stages. The health and safety of staff and residents is not compromised by cost-cutting measures. **[Section 6.2]**
25. Risk management for adult respite services are managed according to the needs of the individual rather than to the facility. Clients of differing abilities, ages and genders who are occupying the same residential area should be appropriately risk managed at all times. **[Section 6.3]**

1. Introduction

“The mark of a truly civilised society is in the way it treats the most vulnerable”

1.1 Background

The Panel had been aware for some time that some parents of special needs children had concerns about the provision of respite care in Jersey and that improvements to the services were being called for. In September 2011, a parent of a young adult with special needs contacted Scrutiny with an email for the attention of the future Health, Social Security and Housing (HSSH) Panel. The email was a plea for help concerning problems she had experienced accessing respite care for her child, and in particular, highlighted that respite care homes were being used as long-term care facilities in some cases.² This was reducing the number of beds available for other families using the respite home, which had a knock-on effect on their ability to access respite and consequently reduced their ability to cope with the burden of being a full-time carer. The email also drew the Panel’s attention to the fact that there were too few Social Workers to assist parents of children and young adults with special needs, especially for those families who were about to make the difficult transition from Children’s Services to Adult Services.³

In a separate incident, the Panel heard of a child with a severe Autistic Spectrum Condition (ASC) being placed with Social Services as a Looked After Child as the result of family exhaustion from caring for a child with extremely aggressive and anxious behaviour.⁴ As the only appropriately staffed location for this kind of care was at Eden House – the Island’s only respite home for children with ASCs and emotional and behavioural disorders – the child was accommodated full-time at the home. This meant that all resources were directed to managing the child in crisis, and the home was effectively closed to other respite users.⁵ In a written submission, a witness described the strain that some families were experiencing as a result of having no access to respite for a number of months.⁶ In the witness’s opinion, this kind of sudden disruption to the respite service could cause further family breakdowns and more children going in to full-time care.⁷

A further two families caring for two children with severe autistic disorders who were accessing respite at Eden House also suffered extreme exhaustion towards the end of 2011, and effectively suffered a family breakdown. The decision was made to take the children into care.⁸ After negotiations between the Health and Social Services Department and the parents, the decision was made to arrange for the children to attend a UK placement at a specialist centre for children with autism.⁹

These cases illustrate the chronic lack of provision for emergency care placements and long term care for children and young adults with disabilities, which have necessitated the use of the respite service during crisis situations. They also suggest that the current level of respite care is inadequate for some families caring for children with extremely challenging behaviour. Given the seriousness of the situation as described by witnesses, the newly formed HSSH Panel felt that an urgent review of the respite care services was required.

¹ Peter Lodder QC, chairman of the Bar Council

² Written submission, 6th October 2011

³ Written submission, 6th October 2011

⁴ Written Submission, 21st January 2012

⁵ Written Submission, 21st January 2012

⁶ Written Submission, 21st January 2012

⁷ Written Submission, 21st January 2012

⁸ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.7

⁹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.7

1.2 The Review

On announcing the proposed review, the Panel received a flood of submissions from parents who were keen to share their experiences of respite care in Jersey. Many were complimentary of the quality of care at respite homes but were clear that the quantity and supply of respite was too little to meet their needs. The unambiguous message was that the all too frequent disruptions to respite were causing families untold stress and threatening their stability. Nearly every parent wanted to know why there was no option for emergency or long-term care for children with special needs other than respite homes.

The Panel put these questions to the Department during the course of the review and identified that the heart of the problem lies in a lack of resources allocated to the provision of respite care. Social Services appear to be 'making do' with limited funding and facilities, forcing already over-stretched budgets to extend even further to accommodate outreach respite and emergency care placements. The Panel was astounded that sums of money recommended for improvements to the Children's Service by Williamson¹⁰ and Bull¹¹ were either untraceable or did not appear to have been allocated to their intended areas.¹² The Panel was also alarmed that a redesign of Children's Respite Services had been identified as a potential means of saving £65,000 in the 2012 Health and Social Services Department (HSSD) Annual Business Plan:

Summary of 2012 Savings Proposals

Ref	Proposal	2012 Proposals	
		£'000	FTE
HEALTH & SOCIAL SERVICES			
HSS - S1	Introduce systems to manage procurement (Procure to Pay System)	250	-
HSS - S2	Review Service Level Agreements (UK & Jersey) with providers	150	-
HSS - S3	Reduction in Energy Consumption	130	-
HSS - S4	Rationalisation of Management Posts	91	-
HSS - S5	Review Occupational Therapy Services, less essential SLA annual increases and other efficiency savings	100	-
HSS - S6	Review process pathways in the hospital to improve efficiency	175	-
HSS - S7	Joint initiatives with Guernsey	150	-
HSS - S8	Rationalisation of H&SS Estate	110	-
HSS - S9	Redesign of Children's Respite Services	65	-
HSS - S10	A&E - appropriate use of service	50	-
HSS - S11	Workforce efficiencies review	50	-
HSS - S12	Redesign of Special Needs residential services	50	-
HSS - S13	Better price negotiations for the purchase of care services	15	-

Upon being asked for clarification, the Department told the Panel that this saving for respite services sits in older adult service and not within children's service provision.¹³ The Panel was at a loss to understand why an already overstretched service should have been identified as an area for savings in the first place, and did not feel that Adult Respite Services was any more appropriate as a vehicle for Departmental savings.

The Department is currently caught up in a spiral of crisis-management with regards to respite care for children, which is impeding proactive planning to meet the future needs of a burgeoning community. The full extent of the Department's crisis management of family breakdowns was revealed during a Public Hearing with the Minister for Health and Social Services.¹⁴ The Panel learned that on more than one occasion in the recent past Robin Ward – the Island's only ward

¹⁰ The States of Jersey Department for Health and Social Services Department (2009), Williamson Report: Implementation Plan

¹¹ Bull, K. (2002), Review of the Principals, Practices and Provision for Children and Young People with Emotional and Behavioural Difficulties and Disorders in the Island of Jersey: Final Report for the Education, Health and Social Services and Home Affairs Committees

¹² Information provided by HSSD, 15th March 2012

¹³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.5

¹⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.18

specifically for sick children – had been used as an emergency crisis placement for young people who, for a number of reasons, could not be cared for by their families.¹⁵ The Panel feels that this case clearly illustrates the urgent need for more emergency care provision in Jersey.

During the extensive Public Hearings and site visits to respite care homes for children and young adults, the Panel was consistently struck by the professionalism and commitment expressed by staff working there. In contrast, it was at times dismayed by the quality of their working environments, which were on occasion tired, run down, inappropriate for the client group or unsafe. Furthermore, the Panel was amazed that there are only three small respite care homes specifically for children catering to the differing needs of a population of nearly 100,000 people.

The Panel is convinced that historic under spending in the area of Children’s Services has led to a serious failure on the behalf of the States to protect and provide for this most vulnerable group in society. The “inclusive society” mentioned in the 2012 Draft Strategic Plan is not a reality today in Jersey. We have failed to care for a section of society that is in most urgent need of protection. We have neglected our responsibility to invest in services and structures that help families stay together under the immense pressures of full-time care. And at a time when youth unemployment is skyrocketing, we have overlooked the need to create a community where equal rights are valued and opportunities are open to all, regardless of their level of ability.

In this time of austerity, it is as if those responsible for overseeing expenditure towards respite care services know the cost of everything, but the value of nothing.

During the course of the review the Panel identified that its recommendations for improvements echoed some of those made in previous reviews of the Children’s Service. In particular the Panel is clear that matters for concern raised in this report have also been identified by recent reviews, especially the recently published Care Inspectorate Report *Inspection of Services for Looked After Children*¹⁶. These have not as yet been acted on by the Department, and the Panel urges the Minister to ensure that outstanding recommendations on this and other previous reports are addressed as soon as possible.

The twin aims of this report are to identify the most urgent problems facing respite care users, and to encourage the Department to act swiftly and decisively to address each of the issues highlighted. The Panel feels the first and most important step is for the Department to acknowledge that there are families who have suffered from having a vital support service withdrawn with little explanation and, in some cases, no further support offered. Accepting that there is a problem is the first stage of working together to ensure that the future supply of respite care in Jersey is secure, guaranteed and plentiful.

¹⁵ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.18

¹⁶ States of Jersey Inspection of Services for Looked After Children: A Report for the Children’s Policy Group, States of Jersey, January 2012

2. The Value of Respite Care

2.1 The Reality of Full-Time Care

Raising a child with a severe physical or learning disability requires an intensive and constant level of care.¹⁷ Simple things like washing, dressing, eating and drinking are a daily challenge that requires physical and emotional support.¹⁸ The family provide all the care and support of a full-time professional carer, but without pay, holidays or time off.¹⁹ Research has shown that constant, 24-hour caring and broken night's sleep can make these families ill²⁰ – both physically and mentally. In many cases, caring without a break compromises a family's ability to cope and has an impact on every member of the family. Siblings can feel sidelined by the disproportionate attention devoted to their brother or sister, and constant caring makes it almost impossible to do the kinds of things most families do – go to the cinema, walk on the beach or going shopping on a Saturday.

Anecdotal evidence suggests that the situation becomes more complex at adolescence, when hormonal and physical changes can increase the care burden on the family. This is also the time when parents begin to worry about what will happen to their child once they reach adulthood and what opportunities will be open to them in terms of independent living, jobs, and training, as well as essential support services. Ultimately, all parents' greatest fear is for their child's wellbeing in the event that they are no longer around to support them, a heavy burden to carry alongside the repetitive and strenuous caring activities that must be carried out day to day.

2.2 The Value of Respite Care

Respite care (or short breaks as it is sometimes known in the UK) is an essential support service to help carers cope with the challenges involved with being a full-time carer. Respite care can mean spending time away from home in a residential unit, or having additional support in the home so the rest of the family can go out and do essential tasks. Research has shown that respite care has significant benefits for both children with special needs and carers.^{21,22} In the short-term, children have the opportunity to have enjoyable experiences²³ and socialise with others²⁴ whilst carers and siblings have the opportunity to relax²⁵, do other tasks and spend time with family and friends²⁶. In the long-term, respite care is a valuable way to prepare for an independent adulthood, creating improved physical and emotional health and crucially, allowing participants to lead lives that are as similar to able-bodied peers as possible.²⁷

Adequate respite care gives families the chance to lead ordinary lives. The benefits for the family include a less chaotic home environment, less stress for the carers/parents and a greater sense of well-being for the whole family unit.²⁸ Family units that are given the support to cope with the

¹⁷ Mencap (2003) Breaking point: A report on caring without a break for children and adults with profound learning disabilities. Mencap. London

¹⁸ Mencap (2003) Breaking point: A report on caring without a break for children and adults with profound learning disabilities. Mencap. London

¹⁹ Mencap (2003) Breaking point: A report on caring without a break for children and adults with profound learning disabilities. Mencap. London

²⁰ Carers Week survey 2006 <http://www.carersweek.org>

²¹ Mencap (2003) Breaking point: A report on caring without a break for children and adults with profound learning disabilities. Mencap. London

²² Treneman M. Corkery A. Dowdney L. Hammond J. (1997) Respite-care needs - met and unmet: assessment of needs for children with disability. *Developmental Medicine & Child Neurology* 39 (8): 548-553.

²³ Stalker K. (1992) An Overview of Short Term Care Services for People with Learning Difficulties. *Social Services Research* 41: 25-30

²⁴ Stalker K. (1988) Family-based respite care for children with severe learning difficulties: an evaluation of the Lothian scheme. *Social Services Research* 1 :1-10

²⁵ Hartrey L. Wells J.S.G. (2003) The meaning of respite care to mothers of children with learning disabilities: two Irish case studies. *Journal of Psychiatric and Mental Health Nursing* 10: 335-342.

²⁶ McNally S. Ben-Shlomo Y. Newman S. (1999) The effects of respite care on informal carers' well-being: a systematic review. *Disability and Rehabilitation* 21 (1): 1-14

²⁷ The Social and Economic Value of Short Breaks, Action for Children, December 2009, p.11

²⁸ The Social and Economic Value of Short Breaks, Action for Children, December 2009, p.2

stressors of caring for a disabled child are likely to avoid breakdown, which has positive implications for both the family and the States in terms of a reduced burden of need.

The testimonies of parents who currently use respite care services in Jersey demonstrate the value of regular respite both for the children and their parents:

*“Oakwell is a wonderful place for the children we care for and they are so well cared for, mentally, physically and their personal care is very well looked after. The children love it there. The building itself has a great swimming pool and four bedrooms.”*²⁹

*“Maison Allo has given my daughter confidence to be away from home, an ability to live with others, to make firm friends, to respond positively to other adults in charge and to develop a sense of independence which will hopefully develop further as she grows up. (Opportunities for this type of development are not easy to come by for children with special needs). She loves going once a week and we don't have the stress of worrying about her happiness and comfort.”*³⁰

*“The staff from Eden House are brilliant and if it wasn't for them more children would be in meltdown.”*³¹

Variety Club, who have contributed substantial amounts of funding to the development of respite care services in Jersey were very clear about what they felt the value of respite care to be. In their view, respite care is “*very, very important*” for the benefit of the child and to give physically and emotionally tired parents time to themselves.³² Furthermore, there are significant benefits for the rest of the family in helping them to “*work together as a unit and maybe have a break away...which [does] them the world of good.*”³³

Respite care has been shown to alleviate a major problem of carer stress³⁴, which is particularly acute for children with severe, multiple disabilities³⁵. Reduced carer stress has benefits for the ability of the carer to stay in work and remain financially secure.

Respite is a valuable and essential support service for children and young people with disabilities. Regular access to a range of respite services has significant benefits for users as a source of development, relaxation and social interaction. For families, it provides a welcome break from caring, time to engage in ‘regular’ family activities with their other children and anecdotal evidence suggests that regular respite care can help parents of children with special needs manage the strain on their relationships and general living circumstances.

Respite care can also act as a significant cost-saving measure for authorities. One report³⁶ identified the following long-term outcomes for government and service providers who invest in respite care:

- decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home;
- decreased cost to health service from reduction in parents’, families’ and carers’ stress;
- decreased cost to schools of educating siblings with behavioural and emotional difficulties.

²⁹ Written submission, 24th January 2012

³⁰ Written submission, 3rd February 2012

³¹ Written submission, Gay Waters, 21st January 2012

³² Public Hearing with Variety, 29th February 2012, p.3

³³ Public Hearing with Variety, 29th February 2012, p.3

³⁴ Hoare P. Harris M. Jackson P. Kerley S. (1998) A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care

³⁵ Chan J.B. Sigafoos J. (2000) A Review of Child and Family Characteristics Related to the Use of Respite Care in Developmental Disability Services. Child & Youth Care Forum

³⁶ The Social and Economic Value of Short Breaks, Action for Children, December 2009, p.2

3. The Demand for Respite Care

Around 10 per cent of the world's population, or 650 million people, live with a disability.³⁷ This figure is increasing through population growth and medical advances, according to the World Health Organisation (WHO).

The picture in Jersey reflects these global changes. In November 2011, census results showed that for the first time the population of Jersey had risen to just under the 100,000 mark.³⁸ Anecdotal evidence suggests more babies with complex special needs are surviving thanks to advances in medical interventions at birth.³⁹ ⁴⁰ Furthermore, recent studies have suggested that the prevalence rate for Autistic Spectrum Disorders (ASD) in children is around 1 in 100.⁴¹ In a population of Jersey's size, this would indicate that around 170⁴² children have some form of ASD, and professionals working in the field of special needs have confirmed that numbers of children diagnosed with autism are on the rise.⁴³

Accurately assessing the number of families who have children with special needs and may therefore need respite is a difficult task. A recent report commented that there is currently "no comprehensive data about the number of children and young people with disabilities in Jersey, nor about the nature of their disability."⁴⁴ Data about babies born with special needs is not currently logged or monitored with respect to support services required later in 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 services.⁴⁵

During the course of the review, the Panel was disappointed to find that the current system to assess demand for essential support services operates on the basis of referrals only and is not proactive in meeting the growing needs of the community. The implications of this system will be discussed in the next two chapters.

3.1 The Current Demand

The rapid population growth in Jersey would suggest that the number of families caring for children and young adults with special needs are also on the rise. It would also be expected that a population of nearly 100,000 would present a significant demand for respite care services. However, the Panel was surprised to learn that at present only 39 families are accessing children's residential respite services in Jersey.⁴⁶ Of these, 10 families access respite at Oakwell, 4 access respite at Eden House and 25 access respite at Maison Allo.⁴⁷

Despite being a relatively small user group, their demand for support is high. Families who do not receive an adequate level of respite care are at higher risk of becoming emotionally exhausted and/or breaking down. In some cases, the child or young adult is taken into care as a result. The Panel learned that this has happened recently. Information submitted by witnesses and the Department confirmed that towards the end of 2011, two separate families caring for children with severe autism broke down, leading to the children being placed in the UK.⁴⁸ The Department confirmed that these families were receiving regular respite,⁴⁹ which suggests that the level of

³⁷ Information accessed from UN factsheet on disability <http://www.un.org/disabilities/default.asp?id=18>

³⁸ Reference the census results.

³⁹ Public Hearing with Jersey Mencap, 2nd March 2012, p.11

⁴⁰ Public Hearing with Sharon Eddie, 27th February 2012, p.4

⁴¹ Information accessed from National Autistic Society <http://www.autism.org.uk/about-autism/some-facts-and-statistics/statistics-how-many-people-have-autism-spectrum-disorders.aspx>

⁴² Based on 17,000 children and young people under 18 years living in Jersey

⁴³ Public Hearing with Sharon Eddie, p.4

⁴⁴ Children And Young People: A Strategic Framework For Jersey (R.133) - 2nd November 2011

⁴⁵ Public Hearing with the Minister for Health and Social Services, 27th Feb, p.23

⁴⁶ Public Hearing with the Minister for Health and Social Services, 27th February 2012 p.7

⁴⁷ Public Hearing with the Minister for Health and Social Services, 27th February 2012 p.7

⁴⁸ Public Hearing with the Minister for Health and Social Services, 27th February 2012 p.7

⁴⁹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.8

respite provided by Social Services was in this case not adequate to protect the families from suffering the extreme stress and subsequent breakdown that can occur as a result of being a full-time carer.

The Panel's initial investigations suggested that demand for respite services has always been historically high, but especially so in the light of the recent crisis situations which had shut down the supply of respite temporarily. However, it felt that the Department had failed to fully acknowledge and accept responsibility for these historic and current problems. When asked if the Minister for Health and Social Services and her Department felt content that they provided a "good service", the Minister responded that from "*my point of view... we do provide a good service.*" She later acknowledged that "*we know there is a pressure on this type of service and will continue to be so.*"⁵⁰ The Panel was concerned that the predominant attitude amongst the Department was one of addressing the problem without taking responsibility for its cause.

The Panel also felt there was a disparity in terms of the Department's perceptions of the level of demand in the community, and the demand expressed by other witnesses. In particular, the Panel learned that Senior Officials in the Children's Service felt that there was no further demand from families for respite care beyond those who were already receiving it.⁵¹ The Panel was told by the Service Director for Children's Services that there were no more families waiting for respite at Eden House other than the four families who were currently using it,⁵² and the same applied to Oakwell.⁵³ On both occasions the Service Director also suggested that Oakwell was being utilised to the full extent of its capacity.⁵⁴

Despite these assertions, the Panel heard from a number of sources that they had not had their respite at Eden House reinstated since the crisis situation had shut down the service there in late 2011. The Head teacher of Mont à l'Abbé, who is in regular contact with around 90 families of children with complex physical disabilities and learning difficulties,⁵⁵ confirmed that she knew of families who were still being denied the respite they had been receiving previously.⁵⁶ Similarly a representative from Autism Jersey told the Panel that her son, who was previously accessing respite at Eden House, had "*not had a minute since October*" when the crisis situation arose.⁵⁷ The Services Manager at Autism Jersey also said that she was aware of families in their membership that had not had their respite reinstated following the crisis situation, and in her view were "*getting closer and closer to crisis themselves.*"⁵⁸

This statement was later supported by evidence gathered by email from Autism Jersey members; of the 17 who responded to the question of whether they had had their respite at Eden House reinstated following the suspension in October, 3 responded to say that they had not had any respite since the crisis, and a further 4 stated that they had received some outreach and day service since October but no overnight stays.⁵⁹

The Panel sought to clarify the inconsistency of evidence heard from users and suppliers with the Department on a later occasion. The Director of Children's Services suggested there had been a misunderstanding about what was meant by 'waiting list', and still confirmed that they had "*nobody on a waiting list for any of our services.*"⁶⁰ He also went on to acknowledge that they had had to reduce the services provided because of the pressures caused by emergency placements in respite care homes.⁶¹ The Managing Director of Community and Social Services later suggested

⁵⁰ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.5

⁵¹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.10

⁵² Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.35

⁵³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.30

⁵⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.30

⁵⁵ Public Hearing with Sharon Eddie, 27th February 2012, p.2

⁵⁶ Public Hearing with Sharon Eddie, 27th February 2012, p.13

⁵⁷ Public Hearing with Autism Jersey p.12

⁵⁸ Public Hearing with Autism Jersey p.12

⁵⁹ Confidential evidence submitted 12th March 2012

⁶⁰ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.9

⁶¹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.9

that the term “waiting list” referred to people who are waiting for resources to be allocated to them and confirmed that there was no one in this position.⁶²

The Department’s confusion and lack of consistency regarding waiting lists and/or a reduction to respite services suggests that senior managers in Social Services are uneasy about publicly accepting responsibility for the problems caused by an ad-hoc, case-by-case system for responding to demand. Social Services do not have a proactive approach in extending the offer of respite to individuals who are eligible for support. The Service Director of Children’s Services confirmed that accessing any service within the Special Needs Service – or any Social Service – was only through referral, either through self-referral, or referral through a professional (for example, a GP or teacher).⁶³ He referred to the service as an “*open door service*,”⁶⁴ suggesting that clients must seek out services themselves rather than being picked up in the system.

During the Panel’s investigation, it became clear that a lack of accurate data about the user group and their current and future needs has resulted in a “first come, first served” approach with regard to respite care. The Service Director of Children’s Services confirmed that not every family that has a child with special needs is known to Children’s Services or, in his opinion needs to be:

“There could be families out there, with children or adults, where there is a range of complexities or difficulties, who are choosing to deal with their situation themselves, the adult stuff as well.”⁶⁵

The Panel sought clarification from Autism Jersey on the number of families that currently had a demand for respite care services that was not being met. Autism Jersey suggested it was difficult to ascertain demand for respite care services because some families do not need respite and therefore do not ask, and “*you only know about the people who have reached crisis and require [respite care].*”⁶⁶ Autism Jersey also coined the phrase “*punished for coping*” to describe the fate of families who would like respite, but superficially appear too well off (either financially or emotionally) to be deemed in need of respite care by Social Services.⁶⁷

Key Finding: The lack of regular, sustainable respite care services for the majority of the user group is unachievable based on the current system. The Panel believe that a significant number of families who would benefit from respite care are not receiving it because of a poorly managed approach to assessing demand. A sustainable and reliable respite care service is important to help prevent families reaching crisis point due to the stress of full-time caring.

Recommendation: Demand should be properly assessed by undertaking research aimed at identifying all families who would benefit from respite care.

3.2 Predicting Future Demand

With regard to predicting the future demand for respite care, the Managing Director of Community and Social Services told the Panel that children who will go on to have complex needs and require respite care can be identified very early through a variety of multi-disciplinary services at the Child Development Centre.⁶⁸ The Service Director for Children’s Services also said that adolescence can often be a crisis time for young people⁶⁹ and confirmed that Children’s Services are currently dealing with a cluster of young people who are hitting adolescence with complex special needs and difficult family situations.⁷⁰

⁶² Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.9

⁶³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.10

⁶⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.10

⁶⁵ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.23-24

⁶⁶ Public Hearing with Autism Jersey, 2nd March 2012 p.13

⁶⁷ Public Hearing with Autism Jersey, 2nd March 2012 p.13

⁶⁸ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.15

⁶⁹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.8

⁷⁰ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.8

However, the Director for Children's Services and the Department argued that predictions of demand would always be skewed by a number of factors. First, they felt that the most unpredictable factor in planning for future demand or need was changes in family dynamics, such as family breakdown.⁷¹ Second, it was highlighted that families moving into the Island bring with them a set of specific needs that cannot be planned for.⁷² Third, according to the Managing Director of Community and Social Services, two children with the same diagnosis may take very different paths based on social and clinical reasons, making it difficult to predict which child may require more support and respite care later in life.⁷³

The unpredictability of family breakdown was frequently cited as an explanation for the apparent failure of the Department to meet the demands of the community. The Minister for Health and Social Services said that:

*"...Even with the best will in mind, with all the planning and whatever, we could not foresee [the recent emergency case]. You never know what is going to happen tomorrow."*⁷⁴

The Panel was deeply concerned by this statement, and felt that clear warning signals relating to the recent emergency care cases had been wilfully ignored by the Department. In particular, the mother of the children who later both went into full-time care had previously made a public appeal for more respite through the JEP on 29th February 2009 (Appendix 1).⁷⁵ In the article, she clearly stated that if Health and Social Services did not give her access to more respite care during the school holidays she would be forced to have to put one of her sons into care because of the significant challenges associated with caring for them single-handed.⁷⁶ The response from the then Minister for Health and Social Services, Senator J. Perchard, was that *"we do not provide holiday breaks as a part of our core business."*⁷⁷ The Panel accepts that this was before the current Minister's time in office, but points out that most of her current Service Directors responsible for delivering respite care services were in post when this article was published in 2009. Their significant failure to act quickly and appropriately should be acknowledged with regard to this case.

The Head teacher of Mont à l'Abbé School believes that it is possible to predict demand. In a written submission on the subject of not being able to predict family breakdown, she suggests that family breakdown is often a consequence of needs not being met early enough rather than the breakdown creating the need.⁷⁸ In an oral statement, she suggested that family meltdowns were accelerated by the continual restriction of access to respite service due to crisis-management:

*"The families in crisis then tend to take all of the support, which means that there is none left for those that are not quite yet at crisis, which just means that the people who are not quite at crisis get there quicker..."*⁷⁹

Professionals working in child health and education are clear that early identification of children who may require support later on in life is critical to being able to plan for and respond to those needs as and when they arise. The Head of Mont à l'Abbé School told the Panel that children with special needs who will experience difficulties during adolescence can often be identified as early as age 5 or 6 years and that this forecast will often remain accurate over time.⁸⁰ A representative

⁷¹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.8

⁷² Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.8

⁷³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.8

⁷⁴ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.4

⁷⁵ Article in Jersey Evening Post, 24th February 2009, p.3

⁷⁶ Article in Jersey Evening Post, 24th February 2009, p.3

⁷⁷ Article in Jersey Evening Post, 24th February 2009, p.3

⁷⁸ Email correspondence from the Head teacher of Mont à l'Abbé School, 27th March 2012

⁷⁹ Public Hearing with the Head Teacher of Mont à l'Abbé School, 27th February 2012, p.11

⁸⁰ Private Hearing with the Head Teacher of Mont à l'Abbé School, 27th February 2012, p.3 (with permission)

from Jersey Mencap also said that children with special needs who have particularly challenging needs should not come as a surprise to authorities - they do not suddenly “appear” at age 7 or 8.⁸¹

Furthermore, a community paediatrician who currently sits on an assessment panel for autism expressed his surprise that social workers do not currently identify individuals who are likely to encounter difficulties during their lifetime and who will or may require respite at the point of diagnosis.⁸² Clearly professionals support a system that identifies demand early on and believe that it could work in practice.

Key Finding: The failure on the part of Social Services to proactively identify and support those families in greatest need before they reached breaking point ultimately precipitated two separate family breakdowns and significant disruption to the rest of the respite care service.

Recommendation: The Department should adopt a more proactive approach to assessing demand and develop a range of early intervention programmes to avoid families reaching crisis point. This would prevent disruption to the respite service and to other families receiving regular respite.

3.3 Lack of Data about Demand

Responding to a question about the rise in diagnoses of autism in Jersey, a stakeholder from Jersey Mencap informed the Panel that there is currently no single database in Jersey that holds statistical information about individuals with a diagnosis of autism.⁸³ The witness suggested that the lack of available data was impairing the charity’s ability to keep track of families who might be in need of their assistance. She confirmed that she had contacted the Statistics Unit to see if there was any demographic information about people with disabilities but had been told there was none available.⁸⁴ She also mentioned that the Statistics Unit had suggested that the next Social Survey might develop a question to gauge how many Island residents have special needs.⁸⁵ The witness and the Panel thoroughly supported this idea.

Key Finding: There is no comprehensive data on the number of children and young people with disabilities in Jersey, or the nature of their disability. This makes assessing current and future demand almost impossible.

Recommendation: An information management system should be developed to capture the needs of the island’s families who care for children with special needs. This data should be captured from existing sources of knowledge (i.e. healthcare and education professionals). Consideration should be given to using the next Social Survey to gather comprehensive information about individuals with special needs.

⁸¹ Public Hearing with Jersey Mencap, 2nd March 2012, p.15

⁸² Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.23

⁸³ Public Hearing with Jersey Mencap, 2nd March 2012, p.10

⁸⁴ Public Hearing with Jersey Mencap, 2nd March 2012, p.10

⁸⁵ Public Hearing with Jersey Mencap, 2nd March 2012, p.10

4. The Supply of Respite Care

The Panel learned that the supply of respite care in Jersey is limited and has experienced significant disruption due to respite care homes being used for emergency care placements even though this is not their purpose. The Panel identified three main circumstances in which the current supply of respite care is failing to meet the needs of the community: during emergency and crisis situations, during the transition phase to adulthood, and during school holidays and after school.

4.1 Current Respite Services for Children

Jersey currently has three respite centres that cater for children – Oakwell Children’s Respite Centre, Eden House, and Maison Allo. Oakwell and Eden House are funded and operated by the Health and Social Services Department. Maison Allo is part-funded through a grant from Health and Social Services and run by Les Amis (a charity) in conjunction with Jersey Mencap.

4.2 Oakwell

Oakwell is an adapted 4-bedroom bungalow situated in an upmarket estate to the West of the Island, and was constructed around 20 years ago. The respite home has a Hydrotherapy Pool and sensory garden which were funded by the Variety Club. Variety also purchased a wheelchair friendly car for the home and built a new extension to the home⁸⁶.

Currently the Department provides the following information about the services available at Oakwell on the www.gov.je website:

“Oakwell Children’s Respite Centre offers short breaks and support to families where a child or children within that family has a severe mobility problem or profound and multiple learning difficulties. We offer a flexible and comprehensive range of services, including weekend breaks, holiday care, accompaniment to hospital appointments, support or short break, hydrotherapy pool and sensory garden, nursing care. These services are available over a 24 hour period, 7 days a week, with a skeleton service on bank holidays.”⁸⁷

“We aim to minimise stress within the family and help to maintain a quality family life. We work closely with the professional therapists from the child development team. Each child will have individual care plans drawn up in partnership with parents and therapists. Referrals are made by the community paediatrician. The special needs social worker and the unit manager will meet with parents and allocate the respite according to individual assessed needs. Assessment reviews will continue every 6 months.”⁸⁸

The Panel felt that some of this information is subject to availability and therefore in some cases is misleading. This is based on the testimonies of witnesses accessing respite at Oakwell, especially with regard to the provision of weekend and holiday care and the allocation of respite “according to individual assessed needs.”

4.3 Eden House

Eden House is a 3-bedroom house with a small garden situated in a residential estate just outside of St Helier. It contains 2 bedrooms and a self-contained one-bedroom flat, and provides respite care for children and young adults who are on the autism spectrum and/or with associated complex developmental needs. Variety Club paid to furnish Eden House, which cost £28,000. There is currently no publicly available information about Eden House on the www.gov.je website; however, the Department provided the following information about the respite provision at Eden House to the Panel:

⁸⁶ Information accessed from <http://www.varietyclubofjersey.org>

⁸⁷ Information accessed from <http://www.gov.je/Health/Children/ChildDevelopment/Pages/Oakwell.aspx>

⁸⁸ Information accessed from <http://www.gov.je/Health/Children/ChildDevelopment/Pages/Oakwell.aspx>

“Eden House is also run by Health and Social Services, and provides respite care specifically for children who are on the autism spectrum and/or with associated complex developmental needs. Most children also have associated challenging behaviour. There is no formal age of entry but most users are between 7 and 18 years old. According to best practice, children with ASD who are younger than age 7 are best supported at home. There are currently 2 beds available and a self-contained flat which is attached to the main property.”⁸⁹

The Department told the Panel that *“the current system [of respite care at Eden House] has been very ad-hoc since October when Eden had to respond to full-time placements.”⁹⁰*

4.4 Maison Allo

Maison Allo is a residential house run by Les Amis in conjunction with Jersey Mencap and offers respite for children aged 5 – 18 with mild to moderate learning disabilities. The house is around 30 years old, is situated on a quiet estate in St Saviour, and was donated to Jersey Mencap in an individual’s will. Information from the Les Amis website describes Maison Allo as follows:

“Maison Allo was set up by and run on behalf of Jersey Mencap. This service provides respite for up to 5 children at any given time and is located in a large house in a pleasant, location close to St Helier. In total 24 children access the service here. New referrals come from Special Needs Service.”⁹¹

Figure one shows the overall figures for budgets allocated to the three residential respite care homes in Jersey:

Respite Facility	Budget	Details
Eden House	£570,030	Includes staff and non staff costs
Oakwell	£453,490	Includes staff and non staff costs
Maison Allo	£230,000	HSSD presently have a contract with Les Amis around respite care provision - was originally via Jersey Mencap but since April 2011 has been direct contracted by HSSD.
TOTAL	£1,253,520	

Figure 1: 2011 Budgets for Children’s Respite Homes

4.5 Outreach Respite Services for Children

Outreach respite services for children (sending staff to provide care at the family home) are limited and delivered within the same budget and resource allocation as residential services.⁹² The Director of Adult Services told the Panel that there have been individual cases where packages of outreach care have been delivered to families, usually for short periods of time.⁹³ Funding outreach respite services from the same budget as residential respite means that when demand at a residential care home is high, there is limited resource to allow for outreach services. The Director of Adult Services said that the Department had to be creative with their resource, and delivering outreach is very much dependent on the pressures on residential respite at that time.⁹⁴

⁸⁹ Information from HSSD

⁹⁰ Information from HSSD

⁹¹ Information accessed from <http://www.lesamis.org.je/html/about.html>

⁹² Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.7

⁹³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.7

⁹⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.6

4.6 Current Respite Services for Young Adults

At the time of writing, there are currently two providers of residential respite care for young adults: Highlands Luxury Care Home and the Les Amis Respite Project.

4.7 Highlands Luxury Care Home

Highlands Luxury Care Home is a privately run residential care home that also offers respite care for people over the age of 18 years of age. Highlands Luxury Care Home has been contracted by HSSD to provide a certain amount of residential respite, specifically two residential respite beds and two nursing respite care beds.⁹⁵ Referrals are made by a Social Worker who carries out the assessment to determine the service required and whether it is available, and Social Services make the final decision. Information relating to Health and Social Services' funding of Highlands Luxury Care Home was presented to the Panel but was marked as commercially sensitive confidential information.⁹⁶

4.8 Les Amis Respite Project

Les Amis is a Jersey based Charity which is associated with Jersey Mencap. The main objective is to offer care and support in residential settings to adults with learning difficulties. The Les Amis Respite Project includes The Lodge, a five-bed apartment providing general respite for adults aged 18-65. This is one of the only respite facilities for adults with learning disabilities in Jersey. A breakdown of Health and Social Services expenditure to Les Amis in 2011, including the funding for Maison Allo, is presented in Figure 2:

	Budget 2011	2011 Actual Expenditure
H&SS Social Care	848,786	938,396
H&SS Respite Care	227,004	188,984
Children's Respite (paid to Mencap up to Jun '11)	219,984	219,984
Additional costs paid towards individuals' care		145,834
Total H&SS expenditure to Les Amis	1,295,774	1,493,198

Figure 2: HSSD funding to Les Amis (2011)⁹⁷

Key Finding: There are only three small residential respite homes offering respite care specifically for children with special needs: Oakwell, Eden House and Maison Allo. Furthermore, there are two sites offering respite care services to adults.

Key Finding: Outreach for children is delivered from the same budget as that allocated to residential respite, which restricts available outreach during busy periods.

Recommendation: The Department should ensure that residential and other respite services, including outreach, for both children and adults are fit for purpose and able to cater to both current and future demand.

4.9 Contribution to the Supply of Respite Care by the Third Sector

A significant contribution towards respite care provision has been made by charities such as Autism Jersey and the Variety Club in terms of respite-type services, outreach, guidance for families and funding of respite projects. For the most part third sector organisations rely on charitable donations from donors to support their work, although some (such as Les Amis) provide respite services funded by HSS. The exact contribution that the third sector makes to respite projects is difficult to ascertain, mainly because where charitable organisations have funded

⁹⁵ Panel visit to Highlands Luxury Care Home, 2nd February 2012

⁹⁶ Information received from HSSD, 26th March 2012

⁹⁷ Information received from HSSD, 26th March 2012

specific projects directly (i.e. with no money flow through the Health and Social Services Department) the Department holds no financial records which provide details of total expenditure and/or donations.⁹⁸

4.10 Autism Jersey

Autism Jersey does not offer respite services specifically, but has a number of schemes in place which provide a source of respite from day-to-day caring. These include a fully staffed Easter and summer play scheme, specifically for children with autism, Asperger Syndrome or other associated complex developmental disorders⁹⁹. Autism Jersey also runs a Befriending Scheme, which matches trained volunteers with individuals with Autism, Asperger Syndrome or any other associated complex developmental disorder. The scheme offers people with an ASD the opportunity to have a friend keep them company, which allows other family members to go about their daily business for an hour or so on a regular basis.¹⁰⁰ Autism Jersey currently has 50 matched families receiving on the Befriending Scheme and a waiting list,¹⁰¹ which indicates that demand for support services for children and young people with autism is very high.

The charity mentioned to the Panel that at the moment families are approaching them for the Befriending Service as they are in dire need of respite. The charity was clear that the Befriending Service was intended as a friendship-building activity for the young person rather than official respite, and so felt concerned by this recent influx of demand. Furthermore, Autism Jersey told the Panel that they had been approached by Social Services who were encouraging the charity to use the Befriending Service as a form of respite.¹⁰² This testimony gives an insight into the pressures on the current supply of respite care.

4.11 Variety Club

Whilst not offering respite services directly, the Variety Club of Jersey has made a significant contribution to respite home facilities and is a valuable supporter of underprivileged children in Jersey. Over the last ten years Variety has undertaken various major projects including building a Hydrotherapy Pool and Sensory Garden at Oakwell. It also purchased a wheelchair friendly car, as well as building a new extension to the home.¹⁰³ Variety Club also paid to furnish Eden House which cost £28,000 and donated £8,151.15 to Eden House in 2009 towards other items.

Key Finding: The third sector makes a valuable contribution to funding and supporting respite care in Jersey. Social Services and the third sector would benefit from improving their lines of communication.

Recommendation: The Department should ensure that a formal partnership is entered into with the main third sector organisations in order to deliver the necessary improvements to the range of respite services available to users.

4.12 Other Forms of “Respite”

There are a number of services and activities which, whilst not classed specifically as respite care, do offer parents and children/young adults a break from caring. These include full-time education, after school clubs, activity clubs, day services and employment opportunities.

4.13 Full-time Education

Mont à l'Abbé School provides a broad and balanced education for children with Severe or Profound and Multiple Learning Difficulties (PMLD and SLD) and physical disabilities aged 3-19,

⁹⁸ Information received from HSSD, 26th March 2012

⁹⁹ Information accessed from <http://www.autismjersey.org/Services.htm>

¹⁰⁰ Public Hearing with Autism Jersey, 2nd March 2012, p.3

¹⁰¹ Public Hearing with Autism Jersey, 2nd March 2012, p.4

¹⁰² Public Hearing with Autism Jersey, 2nd March 2012, p.3

¹⁰³ Information accessed from <http://www.varietyclubofjersey.org>

whose needs cannot be met within a mainstream setting.¹⁰⁴ Additionally, the School provides a professional educational support outreach service to help mainstream schools support pupils with special needs. This is coordinated by a School Partnership Meeting, which is attended by the Head of Mont à l'Abbé, the Deputy Head (who co-ordinates school outreach), and the Mont à l'Abbé psychologist.¹⁰⁵

4.14 Activities Outside of School

Mont à l'Abbé offers a variety of after-school clubs for its own primary-school aged children. Alongside this exists a Holiday Activity Scheme solely for pupils attending the school full-time. The scheme operates during the main school holidays and as a general rule operates for five days at Christmas, 10 days at Easter and 25 days during the summer. The number of days is dictated by the length of the holidays and how Bank Holiday dates fall. The service charges are based on a daily rate of £21.00. By application to the financial section of the Special Educational Needs Team, reductions of up to 60% are available.¹⁰⁶

In addition, the Inclusion Project runs a 5 month personal development programme for young people aged 17-25 with special needs to make friends, spend a week in UK on an outward bound course and gain qualifications. This is part-funded by Jersey Mencap.¹⁰⁷

4.15 Further Education, Training and Employment

The Le Geyt Centre provides Adult Day Services for people aged 18+ with profound and complex physical and learning disabilities, as well as services in community settings. Furthermore, employment training also exists to give young adults and carers respite. Highlands College currently offer life skills training for young adults aged 18/19 years of age. This is a practical course aimed at helping them achieve independence as much as possible. Similarly, the Jersey Employment Trust is a cross-departmental initiative intended to develop vocational services for people with disabilities and special needs of working age. The aim of the Trust is to offer training, skill development and support to promote the transition of adult individuals into open employment. It is open Monday to Friday from 8am – 4.30pm. Furthermore, Social Security offers a 'Workwise' service to help people with special employment needs to find work. According to the www.gov.je website, Workwise can help with "*on-the-job support and training, a range of sheltered and open employment opportunities, work-place adaptations and interview skills.*"¹⁰⁸

4.16 Problems with the Supply of Respite Care

During the course of the review, the Panel learned that under certain circumstances, the supply of respite is inadequate to meet the needs of the community. In particular, the Panel identified three relatively predictable 'flash points' at which the current system of respite care experiences significant strain and/or reduces in supply, which are outlined in this chapter. These circumstances are exacerbated by the relative shortage of resources and staff available to deal with an increased demand for respite services. Specifically, staff working across the respite service are pooled to help deal with a client experiencing a high level of demand, which reduces their ability to support other families. The Panel feels that the Department should as a priority improve their staffing numbers to ensure that even under periods of strain the supply of respite care remains stable. This is critical to ensure that other families do not have their support suddenly withdrawn during a 'flash point' for the respite service, as they may suffer a breakdown as a result.

¹⁰⁴ Information accessed from <http://vle.jeron.je/GroupHomepage.asp?GroupID=14891>

¹⁰⁵ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.4

¹⁰⁶ Information accessed from http://www.jerseymencap.org/index.php?option=com_content&view=article&id=25:mont-a-labbe-school&catid=21:mont-a-labbe-school&Itemid=41

¹⁰⁷ Information accessed from: http://www.jerseymencap.org/index.php?option=com_content&view=article&id=168&Itemid=77

¹⁰⁸ Information accessed from <http://www.gov.je/Working/JobCareerAdvice/Pages/FindingWorkSocialSecurity.aspx>

Key Finding: The Panel identified three main circumstances in which the current supply of respite care is failing to meet the needs of the community; during emergency and crisis situations, during the transition phase to adulthood, and during school holidays and after school.

Recommendation: The Community and Social Services Department should be properly resourced and staffed accordingly to ensure that the supply of respite care remains plentiful.

4.17 During Emergency and Crisis Situations

The Panel learned that the supply of residential respite care had experienced significant disruption as a result of homes being used for emergency care placements. Witnesses described the impact that this had caused to their lives:

*“For the last couple of months I haven’t been allocated Monday evenings. I understand this is because there is a child who is “in care” staying at Oakwell. Whilst I am sympathetic about this, I have been offered other days which are not really beneficial to me”.*¹⁰⁹

*“Due to a family going into crisis Eden House has effectively been closed for respite. In the meantime, parents of children with acute behavioural problems have received no respite, but a little outreach in some cases”.*¹¹⁰

*“The current situation where a child with severe ASC has had to be placed with Social Services as a Looked After Child... has resulted in all respite for children on the Autism Spectrum being stopped as the only place for the child to be accommodated was Eden House. The knock on effect this has caused is that many families who may get a short break have had nothing for over 2 months”.*¹¹¹

In his appearance as an independent witness, Deputy Green also confirmed that he had been contacted by numerous constituents who had been allocated a regular respite slot only to lose it when somebody needed intensive or long-term care, and that this was “the problem” in terms of his understanding of the current supply of respite care.¹¹²

The lack of adequate provision, in terms of manpower and facilities, to cope with families going into crisis meant that respite care homes are under almost constant threat of being used as substitute emergency care or long-term care facilities in times of crisis. According to one service user, *“Both (respite) homes will continue to walk a tight rope, as there is still nowhere available for emergency care.”*¹¹³ The disruption to the regular operation of respite care homes had enormous and significant implications for other families who relied upon regular respite to cope day-to-day, as well as upon the staff and Managers of the respite homes.¹¹⁴

The Head teacher of Mont à l’Abbé School informed the Panel that it was not unusual for children with special needs – particularly those with challenging emotional and behavioural disorders – to require care outside of the family home during adolescence.¹¹⁵ She was clear, however, that the lack of an emergency care facility in Jersey meant that respite homes were being used for this purpose, and inevitably this resulted in cuts and stoppages to the service for other families.¹¹⁶

A representative from Jersey Mencap highlighted how the original purpose of respite – as a short break – had been lost because of the too-frequent use of respite facilities for emergency care. She felt that respite should not be precarious for families, rather something they can rely on to allow

¹⁰⁹ Written submission, 7th February 2012

¹¹⁰ Written submission, 1st December 2011

¹¹¹ Written submission, 21st January 2012

¹¹² Public Hearing with Deputy Green, 28th February 2012, p.11-12

¹¹³ Written submission, 1st December 2011

¹¹⁴ Public Hearing with Jersey Mencap, 2nd March 2012, p.14

¹¹⁵ Public Hearing with the Headteacher of Mont à l’Abbé School, 27th February 2012, p.12

¹¹⁶ Public Hearing with the Headteacher of Mont à l’Abbé School, 27th February 2012, p.12

them to plan their day-to-day lives as well as for holidays. In her opinion, families currently accessing respite care services were living with a high degree of anxiety about when the next emergency scenario might occur and reduce or remove their regular respite.¹¹⁷

Jersey is also disadvantaged in not currently having access to any high-level foster carers to provide short term emergency residential placements. The implication of not being able to develop an alternative, home-based model of emergency care is continuing disruption to existing respite provision, as explained by the Paediatrics Consultant:

“What not having that level 3 [foster care] provision speaks to is that if you run at capacity in your respite care provision, you do not have any flexibility. You are then stuck. If a crisis happens, it is going to affect the other children who are currently using that facility because they will not be going to [a foster carer], and hopefully they will not be going to a hospital set-up.”¹¹⁸

The Department acknowledges that the current supply of emergency facilities is inadequate. In response to a question about how the Department plans to respond to the threat of future crises amongst respite care users, the Service Director for Children’s Services was frank in his admission that should another family be faced with a crisis situation, there are simply no emergency beds or placements available other than those at Eden House and Oakwell. In his view, emergency placements or facilities are a “luxury” rather than a necessity:

“We do not have the luxury of having houses sitting waiting, staff sitting waiting for an emergency. That is what this service has had to do, year on year, is to respond to that crisis.”¹¹⁹

In contrast, a variety of stakeholders recognised the cost-saving benefits of investing in emergency care facilities. A representative from Jersey Mencap identified that any plan for developing an emergency care service should take into account the “soft outcomes” of emergency respite in terms of costs saved by securing respite for regular users and therefore preventing other families going into meltdown and requiring costly off-Island placements.¹²⁰

According to the Head teacher of Mont à l’Abbé School, short-term emergency care provision would help break the “spiralling effect”¹²¹ of family breakdown creating strain on existing respite services, which in turn affects other families and accelerates the process leading to breakdown:

“The families in crisis then tend to take all of the support, which means that there is none left for those that are not quite yet at crisis, which just means that the people who are not quite at crisis get there quicker...”¹²²

In her view, “sometimes families need a short term residential provision (e.g. a few weeks) to enable them to get over a personal crisis.”¹²³

Key Finding: Emergency care is currently provided within the two States run respite homes. This has meant that when a respite home is being used for emergency care, other families have not been able to access essential and short-term respite.

Recommendation: The Department should ensure that emergency care facilities are identified as soon as possible to reduce the strain on respite care homes. This is especially important for young

¹¹⁷ Public Hearing with Jersey Mencap, 2nd March 2012, p.14

¹¹⁸ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.38

¹¹⁹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.36

¹²⁰ Public Hearing with Jersey Mencap, 2nd March 2012, p.14-15

¹²¹ Public Hearing with the Head teacher of Mont à l’Abbé School, 27th February 2012, p.10

¹²² Public Hearing with the Head teacher of Mont à l’Abbé School, 27th February 2012. p.11

¹²³ Email from the Head teacher of Mont à l’Abbé School, 27th March 2012

people with autism who are more likely to become difficult to manage in the home during adolescence.

4.18 Long-term care facilities

At present, both Health and Social Services-run respite facilities are currently being inappropriately used as a long-term care homes for some residents. The Service Director of Children's Services confirmed that there is one full-time resident currently at Eden House, and one full-time resident at Oakwell.¹²⁴

Long-term residents in respite care homes disrupt the original intention of a respite service, which is to provide short breaks for a variety of families, and for the staff to interact with different users. In addition, long-term residents also have a significant and costly impact in terms of bed space. Due to the limited amount of respite beds currently available, even one long-term resident taking up a bed space can create a situation where a number of families have to have their respite reduced.

The Panel was informed that the Department intends to refurbish Heathfield (an empty site which formerly housed children in care) to provide long-term care placements for young people with emotional and behavioural disorders who are already in care. In particular, the Department aims to provide a small unit for the two children on placement in the UK on their return, and also the young person who is currently in full-time residence at Eden House. In total, this unit would house three individuals in separate quarters. The Panel was told that the Department is currently taking advice from architects with expertise in the design of residential homes for young people with autism, as well as looking into staffing.¹²⁵ There are some concerns about how this project will be funded:

*"But obviously there is a significant sum of money attached to that to provide that. It is not funding that we currently have, so we are in discussion both with our Minister and Chief Executive about the funding of that."*¹²⁶

The Panel recognises this is a positive step forward, but also identified a chronic short-termism on the part of the Children's Service in terms of planning an adequate supply of facilities for future crisis scenarios. The Panel asked the Service Director of Children's Services if he did not think there was a degree of short-sightedness in only constructing a unit to meet the existing crisis cases, given that diagnoses of autism in particular were on the rise and therefore future demand will increase. The Service Director's response was that his focus was only on the current demand.¹²⁷ Furthermore, he stated that:

*"...The professionals are telling us of the other people who are accessing respite currently, there is none of them who are requiring any further specialised support. The message coming from the families and from the professionals, if the other families continue to get their respite they are okay."*¹²⁸

This comment illustrates a broader problem with the way the supply of respite care is managed by the Department. Rather than starting by identifying the current and future needs of the community and basing a supply model around this quantifiable data, need is responded to as and when it arises and/or is brought to the attention of Social Services. Continuing to operate a model along these lines, rather than building for the future inevitably means that the supply of respite care will always be under strain.

Key Finding: The lack of long-term care facilities for children with complex needs means that respite homes have been used for this purpose, to the detriment of other residents.

¹²⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.7

¹²⁵ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.7-8

¹²⁶ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.7-8

¹²⁷ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.8

¹²⁸ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.8

Recommendation: The Department should prioritise plans for long-term care and ensure these are in place as soon as possible. Any provision should take into account an expansion of demand and be able to cater for multiple crisis scenarios occurring at any one time.

4.19 During the Transition Phase to Adulthood

The transition period between Children's and Adult Services was the overwhelming concern for nearly all the parents who submitted evidence to the Panel. Witnesses expressed a great deal of fear when they contemplated their children's next steps after the end of full-time education and/or respite care at Oakwell, Eden House or Maison Allo.

4.20 Witness's Experiences of Transition

The Panel heard that the current system to plan for and provide for this important step was felt to be poorly managed, inefficient and inadequate to meet the needs of the user. The Vice Chairman of Autism Jersey felt that there was no strategy in place for the provision of respite care for children who turn eighteen,¹²⁹ and was frustrated by Social Service's lack of proactivity in identifying and working with older children approaching adulthood:

*"They should not be a surprise. You cannot suddenly say: "Eighteen, whoops, where did he come from?" They have been in the system since they were toddlers and it should not be a surprise and we should not be having this fight for service. It should be a properly-managed transition programme."*¹³⁰

Another witness who had formerly lead a school for autism in the UK expressed concern about the fact that support offered during the transition period does not appear to be planned and are not in place early enough. In her experience of best practice around transition, adult services are brought in when the child is in year 9 (age 13) and stay alongside them until they are ready to leave the Children's Service. This means there are no "surprises" along the way and the service providers are aware of the child's specific needs well in advance. The witness felt that it would be best practice to ensure that every child has a personal care plan to take them from Children's to Adult Services.¹³¹

In particular, the Panel was surprised to hear that even if a family has a social worker they have to be reassigned a new one when the child turns 18 - they effectively become a "closed case", and a valuable working relationship is lost. The Business Manager of Jersey Mencap highlighted that there is currently no handover between the child social worker and adult social workers, and no named social worker for the family to work with. The family must start again by contacting Social Services and getting a named social worker to refer them for the adult respite services. In her opinion, the current transition planning is not coping with demand:

*"It seems as if a fortnight before people [turn] 18, alarm bells are ringing off all over the place."*¹³²

Appearing as an independent witness before the Panel, Senator Routier stated that he felt that social worker support after the end of school for children with special needs was insufficient:

*"When a child is at school, I think that [social worker support] is probably better than it is as soon as they leave school. As soon as they leave school, I think it falls down. Because you have got the whole school team around the child and there are regular meetings and things can get picked up, but once a child leaves school, I think it becomes very difficult."*¹³³

¹²⁹ Public Hearing with Autism Jersey, 2nd March 2012, p.10

¹³⁰ Public Hearing with Autism Jersey, 2nd March 2012, p.10

¹³¹ Public Hearing with Gay Waters, 2nd March 2012, p.13

¹³² Public Hearing with Jersey Mencap, 2nd March 2012, p.6

¹³³ Public Hearing with Senator Routier, 28th February 2012, p.12

A number of parents expressed frustration at the notion that their children no longer needed the same level of respite care just because they had turned 18. A witness from Autism Jersey whose transition-age son accessed respite at Eden House was amazed when not only her respite was withdrawn because of the crisis situation, but also the transition planning. After repeatedly contacting staff at Eden House for an explanation as to when her respite and her son's transition planning would be reinstated, she was surprised to be told that staff were not aware that her son would need respite any more when he went into Adult Services.¹³⁴

The Panel, parents and stakeholders were dismayed at the precariousness surrounding continuity of respite care for young adults with life-long disabilities. There appears to be an attitude amongst providers that when a child turns 18, they should no longer need respite, despite having the same disability and family situation as before. Representatives from Autism Jersey were clear in their recommendation that all services for people with autism should be life-long, not just respite. They felt that the cut off at 18 and change of social worker created a period of huge disruption and anxiety for families and their children, a view shared by nearly all the witness who were experiencing a transition. One witness summarised her frustration with the current system:

*"You do not suddenly stop being autistic because you achieve your 18th birthday. It is a life-long disability."*¹³⁵

Both of the two States Members who volunteered to speak to the Panel about their experiences of caring for children with special needs were clear that they felt the problems with the transition process were related to with the way funding is currently allocated. Deputy Green told the Panel that the haste with which disabled children are passed into Adult Services is "almost indecent" and he felt sure that this was down to "budgetary" issues.¹³⁶ Both he and Senator Routier argued that the current system of allocating funding to an individual from a centralised budget created a precarious situation in which the needs of the individual take second place to the amount of money available. Both Members felt that a system of allocating every individual a personalised budget which followed them throughout their life would ensure that they were able to buy the services they required at any given stage, be it respite or another service.¹³⁷

Key Finding: Families face significant challenges when their child reaches the age of 18 and moves from Children's to Adult Services, especially as the system does not provide for a personal care plan or individualised budget. Instead, access to necessary support services depend on the resources available within the Adult Services budget at the time.

Recommendation: Transition planning to start as early as possible and Children's and Adult Services should communicate better to ensure services do not "drop off" at 18 years. Ultimately, all children with special needs should have a personal care plan and individualised wraparound budgets that follow them throughout their lives, to ensure that the transition period is as seamless as possible.

4.21 Opportunities for 18+ Respite Users

Parents were almost unanimous in their praise of the Special Education Needs (SEN) provision in both mainstream schools and at Mont à l'Abbé , in terms of staff excellence, quality facilities and a commitment to inclusive and stimulating education. In addition, most parents were extremely happy with the quality of respite services for children up to the age of eighteen (when they were available).

The high quality of schooling for special needs children coupled with regular social interaction offered by children's respite 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

¹³⁴ Public Hearing with Autism Jersey, 2nd March 2012, p.11-12

¹³⁵ Public Hearing with Autism Jersey, 2nd March 2012, p.10

¹³⁶ Public Hearing with Deputy Green, 28th February 2012, p.12

¹³⁷ Public Hearing with Deputy Green, 28th February 2012, p.21

support. The reality, however, does not meet this expectation. The main issue following the end of education was the struggle for young adults with special needs to find any kind of meaningful employment. Some parents questioned the value of an education system that raised expectations of a fulfilling adult life in this way:

“...You have to ask yourself... why we bother to take them through the education system, build up their expectations and then say: “But we do not have anything for you.” You have to ask yourself that. I think it is soul destroying frankly. We told them that they are going to be able to do this and they are going to be able to do that and when they leave, they sit at home because there is nothing there for them.”¹³⁸

Currently, day services (in the traditional sense) are offered by Le Geyt, which was built as a training centre in the 1960's and offers activities in the centre and out in the community. Some parents were satisfied with the provision at Le Geyt, whilst others were concerned at the apparent lack of meaningful stimulation offered to residents. A representative from Autism Jersey told the Panel that young people go from a very lively, encouraging and productive environment at Mont à l'Abbé and at their respite provider, to day care provision like Le Geyt which is hugely different in terms of structure, location and activities.¹³⁹

Key Finding: Once young people leave full-time education the range of available respite type services changes dramatically. Furthermore opportunities available for young adults with special needs in Jersey in terms of access to training, employment or day services are limited.

Recommendation: The Department should ensure that close working with other government and third sector ages is undertaken to further develop the range of services available for young adults with special needs. Good relationships with local employers should be fostered to ensure that there are opportunities for young adults with special needs to make a contribution to society.

4.22 Financial Burdens

Compounded with these fears about the drop-off in terms of stimulation were financial concerns about the sudden and significant increase in care burden due to the end of full-time education and children's respite services. The Panel learned that many parents who had previously held down jobs whilst their child was occupied at school and regularly receiving respite care were faced with a dilemma once school ended. The problem of providing full-time day care to a young adult previously at school 5 days a week, 34 weeks a year meant that some parents have to give up their jobs to be a full-time carer.^{140 141} This not only significantly reduces their income, creating financial pressures on the family's ability to cope, but also increased the likelihood of their needing some form of additional financial support.¹⁴²

Alternatively, some parents are forced to work fewer hours after their child turns 18 in order to retain the same level of financial support from Social Security. One parent told the Panel that she had been forced to take an evening job during the week so that she could juggle care of her son with her husband and still receive income Support:

“It was something that I never wanted to do, but I just could not see how my family would survive if I did not do something to try and pull it back together. Therefore, I am on Income Support in effect where really I am perfectly capable of working and would have liked to have carried on working, but then my son has to come first and my family.”¹⁴³

¹³⁸ Public Hearing with Deputy Green, 28th February 2012, p.22

¹³⁹ Public Hearing with Autism Jersey, 2nd March 2012, p.13

¹⁴⁰ Public Hearing with Sharon Eddie, 27th February 2012, p.14-15

¹⁴¹ Public Hearing with Autism Jersey, 2nd March 2012, p.13

¹⁴² Public Hearing with Autism Jersey, 2nd March 2012, p.13

¹⁴³ Public Hearing with Autism Jersey, 2nd March 2012, p.13

Key Finding: At the end of full-time education the personal commitment required from the carer increases dramatically. As a result some have to give up work which affects their ability to deal with the day to day financial matters that many of us take for granted.

Recommendation: The Department should ensure that the parent's ability to work is supported as much as possible and resources for adult respite care and outreach are increased where appropriate.

4.23 Health and Social Services' View of the Transition Service

The Department's view of the transition between Children's and Adult Services was remarkably different to the experiences of witnesses.

"Children do not immediately transfer from Children's Service to Adult Service. Every child and family is different, therefore each scenario is assessed by the Children's Social Worker who will make appropriate referrals, and complete forms for bespoke services if required. Children can be referred for an Adult Social Worker at the age of 16/17yrs. It is expected that Adult Social Workers get involved by the age of 17.5yrs, ready to take over when the child turns 18yrs. School has a transition policy for children with a Record of Need, which begins when the child is 14yrs. Some children leave school at 16yrs - therefore the early transition planning is essential." ¹⁴⁴

Some witnesses highlighted the recent changes to the service structure at Social Services as being partly responsible for the gaps in provision and support during the transition stage. A representative from Jersey Mencap suggested that Social Services "missed a trick" when restructuring in not creating a standalone transition team alongside Children, Adult's and Older People's Service. In her opinion:

"A transition team would be the answer to so many people's issues." ¹⁴⁵

Key Finding: The Department's perceptions of the transition service are unrealistic. The current transition system does not work properly, reflecting problems with the delivery of transition support by two separate services.

Recommendation: A standalone 'Transition Team' should be established to help parents and children navigate the difficult journey from Children's to Adult Services.

4.24 During School Holidays and After School

Nearly every parent of a child with special needs mentioned the school holidays as a source of anxiety in terms of the supply of respite care. One witness summarised the problem facing most parents of school-aged children:

"Every summer holiday was a nightmare because if he was not in school I had him for 6 weeks." ¹⁴⁶

The witness also spoke about having to fight to get more than one Saturday a fortnight's respite during the summer holidays, and told the Panel that she had been asked by Social Services to pay to get even half a day's support. In her own words *"I just knew our family was going to fall apart if I did not do something."* ¹⁴⁷

Another critical problem with regard to respite care during the school holidays is that of care ratios outside of term-time. Currently, the parent of a child assessed as needing a 2:1 or 3:1 care ratio at

¹⁴⁴ Information received from HSSD, 26th March 2012

¹⁴⁵ Public Hearing with Jersey Mencap, 2nd March 2012, p.5

¹⁴⁶ Public Hearing with Autism Jersey, 2nd March 2012, p.14

¹⁴⁷ Public Hearing with Autism Jersey, 2nd March 2012, p.13

school or in the respite home is expected to be able to handle their child on their own - with no additional support provided - at home during the summer holidays.¹⁴⁸ According to a stakeholder from Autism Jersey, *"It does not work."*¹⁴⁹

Furthermore, children with special needs are at a distinct disadvantage compared to their able-bodied peers in terms of the choice of holiday and after-school activities open to them. The Business Manager of Jersey Mencap told the Panel that the kind of holiday clubs and activity camps that are available for children at mainstream schools up to age 12 simply are not available for young people with learning disabilities.¹⁵⁰ This was acknowledged to be partly due to the expense of staffing and resourcing activity groups for children with special needs, but the lack of opportunity for development outside of the classroom was felt to be a significant problem by the Panel.

Testimonies about the school holidays from witnesses suggested that the sudden drop in hands-on support combined with the lack of available activity clubs for children and young adults with special needs meant that the school holidays in particular are a "danger zone" for family meltdown:

*"There are some very long holidays out there and some parents find them very stressful. It is a bit of a crisis point."*¹⁵¹

Key Finding: Children with special needs are at a distinct disadvantage compared with their able bodied peers in terms of choice of holiday and after-school activities. This places an additional burden on the carer, who is trying to balance work and family life with the needs of their child.

Recommendation: Where a childcare ratio is 2:1 or above within the school or respite facility, support should be tailored to reflect that additional need in the home environment.

Recommendation: Resources should be identified to fund more holiday club provision, in conjunction with the third sector and Mont à l'Abbé School.

¹⁴⁸ Public Hearing with Autism Jersey, 2nd March 2012, p.28

¹⁴⁹ Public Hearing with Autism Jersey, 2nd March 2012, p.28

¹⁵⁰ Public Hearing with Jersey Mencap, 2nd March 2012, p. 7

¹⁵¹ Public Hearing with Jersey Mencap, 2nd March 2012, p. 7

5. Accessing Respite Services

Many witnesses interviewed during the course of the review felt that accessing respite services was intimidating, difficult and bureaucratic. Impediments to access identified by witnesses included perceptions of stigma, a lack of social workers, a feeling that access was being restricted to save resources, poor communication of respite services available and a lack of clear policy and/or criteria for professionals and parents with regard to eligibility for respite care.

At a focus group of parents of children with multiple and profound disabilities¹⁵² most were happy with the level of care offered by the respite service they received but were very critical of how hard it was to gain access to respite. In some cases, children with more profound and visible physical disabilities were perceived as getting access to more respite than others, and whilst some parents had access to a number of different social workers and plenty of regular respite, others had none. Communication and information regarding respite was felt to be “ad hoc” and parents felt they were more likely to find out how to access services from other parents rather than from professionals.

Some parents also felt unhappy with the current assessment process for accessing respite care.¹⁵³ The Record of Need meeting, for example, takes place once a year at the school and parents felt it was up to them to contact the relevant professionals involved in their child’s education and health and social care, and ask them to attend.¹⁵⁴ According to some parents, it is not always guaranteed these individuals will turn up, “especially if they feel they’re not in the loop about a specific child.”¹⁵⁵

One parent likened the struggle to access respite care services after receiving a diagnosis of special needs to being “thrown to sea without a life raft”¹⁵⁶, and there was a general feeling that parents are left to “get on with it” rather than being supported by Social Services from diagnosis onwards. Many parents spoke of access to respite services as a “fight” or a “struggle.”¹⁵⁷ Finally, one of the most persistent perceptions about accessing respite care was that “the louder you shout, the more you get.”¹⁵⁸ Parents were unhappy with a service that appeared to favour the more vocal members of the community at the expense of those less able or inclined to complain. This view was substantiated by the Head teacher of Mont à l’Abbé :

“...It is very difficult to be objective and to look at which families are coping and which are not, because some can appear to cope because that is just the way they are, and actually they might be in the greatest need.”¹⁵⁹

5.1 The Current System of Access

In the UK, support services must be provided by law to disabled children (classified as “children in need”) under the Children Act (1989)¹⁶⁰ and carers under the Carers and Disabled Children Act (2000).¹⁶¹ Regulations impose a duty on local authorities in England to provide respite to carers of children (Appendix 2). However in Jersey there is no statutory requirement to provide respite care for children and young adults with special needs.

¹⁵² Focus Group held at Mont à l’Abbé School, 22nd February 2012

¹⁵³ Focus Group held at Mont à l’Abbé School, 22nd February 2012

¹⁵⁴ Focus Group held at Mont à l’Abbé School, 22nd February 2012

¹⁵⁵ Focus Group held at Mont à l’Abbé School, 22nd February 2012

¹⁵⁶ Focus Group held at Mont à l’Abbé School, 22nd February 2012

¹⁵⁷ Focus Group held at Mont à l’Abbé School, 22nd February 2012

¹⁵⁸ Focus Group held at Mont à l’Abbé School, 22nd February 2012

¹⁵⁹ Public Hearing with Sharon Eddie, 27th February 2012, p.9

¹⁶⁰ Department of Health (1989) Children Act. HMSO. London

¹⁶¹ Department of Health (2000) Carers and Disabled Children Act. HMSO. London

Key Finding: The States do not have a duty of care to provide respite care for families in Jersey, nor a clear social policy that enshrines the rights of the most vulnerable in society. This is in contrast with almost every other UK jurisdiction, as well as the Isle of Man.

Recommendation: Community care legislation should be brought in to safeguard the rights of vulnerable children and young adults with regard to respite and other support services.

5.2 Special Needs Service

According to information from the www.gov.je website, services such as respite care are accessed through a referral from the Special Needs Service, a “lifelong, children and adult service providing social care and support for people in the community.”¹⁶²

Children with special needs are defined by the Special Needs Service as either having a learning disability, an autistic spectrum disorder, a physical disability or a sensory impairment. Adults with special needs are defined as having a diagnosed learning disability or an autistic spectrum disorder. Adults with a physical disability or a sensory impairment seem to fall outside the criteria of the Special Needs Service.¹⁶³

Currently, the system of access depends on someone being referred by a GP or by contacting the Special Needs Service directly.¹⁶⁴ Furthermore, two ‘duty officers’ are meant to be available on a daily basis to provide advice and arrange for an assessment of need “in appropriate cases.”¹⁶⁵ There is no dedicated 24-hour phone line available for carers with children who are in urgent need of help or protection, other than a call-back system which is routed via the police. Parents felt this was inappropriate and did not elicit the kind of urgent support that they required.¹⁶⁶

5.3 Assessment of Need

The Panel learned that following a referral to the Special Needs Team, an Assessment of Need should be produced by the Social Worker assigned to the case. This document is supposed to outline the specific needs of the individual and determines the level of support required, including recommendations around access to respite care. It is not supported by legislation because there is no community care legislation in Jersey however; the Department describe it as being underpinned by best practice.¹⁶⁷

5.4 Record of Need

A Record of Need is similar to the Assessment of Need, and is an educational assessment for school-age children.¹⁶⁸ It is reviewed annually by a group of relevant professionals from Education, Health and Social Services and updated as necessary.¹⁶⁹ According to the Head of Mont à l'Abbé School, the Record of Need may identify or recommend other services relevant to the child, but does not have the power to summon or enforce particular courses of action.¹⁷⁰ For example, during the Annual Review Meeting a recommendation may be made that the child be considered for respite. This recommendation would then be passed on through the social work team and managed remotely from the school thereafter.¹⁷¹

The Head of Mont à l'Abbé also explained that if a child is already receiving respite, the respite provider can attend the Annual Review Meeting with the intention to address any needs and/or

¹⁶² Information accessed from <http://www.gov.je/Health/Support/SocialServices/Pages/SpecialNeeds.aspx>

¹⁶³ Information accessed from <http://www.gov.je/Health/Support/SocialServices/Pages/SpecialNeeds.aspx>

¹⁶⁴ Information accessed from <http://www.gov.je/Health/Support/SocialServices/Pages/SpecialNeeds.aspx>

¹⁶⁵ Information accessed from <http://www.gov.je/Health/Support/SocialServices/Pages/SpecialNeeds.aspx>

¹⁶⁶ Focus Group held at Mont à l'Abbé School, 22nd February 2012

¹⁶⁷ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 31

¹⁶⁸ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.6

¹⁶⁹ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.6

¹⁷⁰ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.7

¹⁷¹ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.7

provide a consistent environment between school, home and respite.¹⁷² The Panel understood that team working between Education, Social Services and Health Services relies largely on goodwill and not statutory obligation. The Head of Mont à l'Abbé told the Panel that if a child has been allocated a social worker they will always be invited to attend the annual review meeting. Social workers receive all the dates of Annual Review Meetings a year in advance, but according to witnesses their attendance is neither mandated nor always observed.¹⁷³

5.5 How do these assessments work together?

The Record of Need and Assessment of Need to some extent replicate the work of one another, but are reflective of differing departmental language and priorities¹⁷⁴. The Director of Adult Services said:

*“Our assessment is to establish what support is required out in the community and at home. The [different assessments] do come together; they are not separate pieces. It is just that, as a record, Education have their title and their documentation, and we have ours within the social worker’s assessment.”*¹⁷⁵

In the UK, the “Every Child Matters” Green Paper proposed the introduction of a Common Assessment Framework as a central element of a strategy for helping children, young people and their families with areas of need. The consultation document highlighted that most agencies and practitioners who work with children and young people to achieve various priority outcomes undertake some form of needs assessment to determine what services should be offered in each case.¹⁷⁶ The document also highlighted that because each agency has its own approach to assessment, there is a lack of coordination and consistency between them, in some cases leading to important needs not being picked up early enough, or at all, and in other cases leading to agencies asking families for similar information time and time again.¹⁷⁷ This is particularly pertinent to the issues surrounding the Assessment of Need and Record of Need in Jersey.

The Panel was informed that the Department is looking to pilot the Common Assessment Framework as Jersey has not yet reached the point of everyone contributing to one singular assessment. It is hoped that a Common Assessment Framework would provide a more joined up approach¹⁷⁸ which is clearly lacking in terms of assessment. The Consultant Paediatrician at Jersey General Hospital informed the Panel that Jersey is lacking a degree of pro-activity in terms of assessing all children who either have a diagnosis or who have a recognised special need.¹⁷⁹ Furthermore, he said that every one of those children and families would require initial assessment to make the decision whether they do or do not require, or would benefit from, respite provision.¹⁸⁰

Key Finding: There is a need for a more coherent, joined-up approach to assessment to address the holistic needs of the child and the family. Eligibility for respite care is dependent on someone being referred by a GP or by contacting the Special Needs Service directly. Following a referral to the Special Needs team an Assessment of Need should be produced by the Social worker assigned to the case. The Department is looking to pilot the Common Assessment Framework as Jersey has not yet reached the point where all parties contribute to one singular assessment.

Recommendation: A Common Assessment Framework should be introduced to make assessment quicker and easier to understand, and to ensure that all relevant parties are involved

¹⁷² Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.7

¹⁷³ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.7

¹⁷⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 31

¹⁷⁵ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 32

¹⁷⁶ Common Assessment Framework Consultation, Department for Education and Skills, 2004

¹⁷⁷ Common Assessment Framework Consultation, Department for Education and Skills, 2004

¹⁷⁸ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 33

¹⁷⁹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 33

¹⁸⁰ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 33

at each stage. The Record of Need should be strengthened to ensure the overall needs of the child are met, as well as the educational needs.

5.6 Impediments to Accessing Respite

During the course of the review, the Panel heard a number of statements from witnesses regarding what they felt were impediments to accessing respite care.

5.7 Stigma and Perceptions of Unfair Allocation

A number of the witnesses were intimidated by the prospect of seeking a social worker and the referral process through Social Services generally. One group of parents who care for children with disabilities expressed the following view:

“People are confused about Social Workers. Some might think that being offered one implies they are involved in child abuse.”¹⁸¹

Witnesses who attached stigma to getting a social worker or contacting Social Services often expressed the feeling that those families who were more outspoken in broadcasting their needs to the authorities had greater access to services. The Panel understood that some families did not want to be seen to be going “cap in hand” to Social Services, and many parents were absolutely clear that caring for their child was their responsibility, first and foremost.

This is a potential explanation for the discrepancy in the Department’s understanding of demand for respite care and the evidence that the Panel heard in Hearings and through submissions (Chapter 6). The stigma associated with Social Services combined with a family’s sense of obligation as primary carers may be stopping parents walking through the doors of Social Security or picking up the phone to ask for a Social Worker, though their needs might be great. It is not surprising that the Panel heard that many parents who did not want to complain vociferously felt like they were being “punished for coping.”¹⁸²

This contention was supported by the testimony of the Consultant Paediatrician, who suggested that it takes a “very particular kind of person” to go through the doors of Social Services without advocacy from a support worker. In his view, without any kind of support some people never get referred:¹⁸³

“I think there are probably many families out there who are struggling, who I encounter from time to time, who have never been involved with Children’s Services because they have never either had the opportunity to do so or they have never felt the gumption, if you like, the strength and the fortitude that it takes to admit that: “Actually I need some help.”¹⁸⁴

The Department acknowledged it was aware of the stigma associated with Social Services, and agreed that there was a “really important”¹⁸⁵ need to “re-profile”¹⁸⁶ community services more broadly. The Director of Adult Services alluded to the purpose of this report being able to guide that process within the current year.¹⁸⁷ Furthermore, the Minister acknowledged that negative perceptions of the work of Social Services might be acting as a “hurdle”¹⁸⁸ to people accessing services. Her suggestion of rebranding Social Services as Community Services was warmly received by the Panel.¹⁸⁹

¹⁸¹ Focus Group Held at Mont à l’Abbé School, 22nd February 2012

¹⁸² Public Hearing with Autism Jersey, 2nd March 2012, p.13

¹⁸³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.24

¹⁸⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.24

¹⁸⁵ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.11

¹⁸⁶ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.11

¹⁸⁷ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.11

¹⁸⁸ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.22-23

¹⁸⁹ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.22-23

Key Finding: The referral process for respite care can be intimidating for some parents, and without the support of an advocacy worker some families may never be able to access the necessary support.

Recommendation: Community and Social Services should be re-named Community Services as part of a wider programme of communication about services available to members of the community.

Recommendation: Advocacy services should be established to help parent's navigate the referral process and to access respite.

5.8 Restricting Access to Protect Resources

An expert in education for young people with autism told the Panel that in her experience, some professionals are being forced to delay diagnoses because they are aware that a diagnosis carries with it an obligation to refer the individual on to relevant services.¹⁹⁰ She felt that in Jersey there was a reluctance to diagnose a child with autism, as the relevant services were simply not in place to support autistic children. This acts as an impediment to accessing relevant respite services because it is necessary to have a clear diagnosis of autism on the Record of Need in order for the family to access the right kind of support. The witness also gave testimony about the impact that a non-diagnosis can have on the individual's understanding of their condition:

"Often these young people need a diagnosis to know what [kind of disorder] they have... one child said to me: "You mean I am not going mad?"¹⁹¹

Stakeholders from Autism Jersey broadly agreed with this evidence. In response to being asked whether they felt that issues about the availability of resources were affecting professionals' inclinations to diagnose people with autism, the witness responded that this was "a possibility."¹⁹²

Furthermore, another representative from Autism Jersey highlighted that some young people upon referral may receive a letter from Child and Adolescent Mental Health Services (CAMHS) which directs them to Autism Jersey for support without actually having diagnosed them first with autism.¹⁹³ The Panel felt concerned that in some cases diagnosis is being avoided to try and prevent people from entering the system due to the lack of resources available.

The Panel also heard from an education professional that levels of staffing at Eden House are at the same level as the provision at Aviemore in the 1990's.¹⁹⁴ Given the increase in awareness and diagnosis of Autistic Spectrum Disorders (ASD) in that time period, the Panel felt that this could be impairing the ability of the service to respond to the growing needs of the community.

Key Finding: Some professionals working with children with autism are concerned that clients are not receiving diagnosis early enough, or in some cases, at all because of a squeeze on resources available for this client group. This also impairs the ability of the service to respond to new instances of need as they arise.

Recommendation: The current criteria for diagnosing children with autism should be clarified. The financial consequences should not be the determining factor when deciding the level of respite required by a diagnosis. Resources should be increased to allow respite providers to respond to new clients as appropriate.

¹⁹⁰ Public Hearing with Gay Waters, 2nd March 2012, p.11

¹⁹¹ Public Hearing with Gay Waters, 2nd March 2012, p.11

¹⁹² Public Hearing with Autism Jersey, 2nd March 2012, p.30

¹⁹³ Public Hearing with Autism Jersey, 2nd March 2012, p.30

¹⁹⁴ Written submission from Gay Waters, 21st January 2012

5.9 A Lack of Clear Policy and/or Criteria

On a number of occasions the Panel sought to clarify the criteria used by Social Services and professionals to assess an individual's eligibility for respite care. The Panel was sent basic eligibility criteria relating to diagnosis by the Department (see Appendix 3), but no formal policy about the delivery of respite care appears to be in evidence.

The Paediatrics Consultant explained how professionals currently determine a family's access to support and respite care based on "gut instinct" rather than any criteria:

"Often it is professional judgment; it is not about any specific laid-down criteria. It is about people's intuition and understanding with their professional careers behind them to say: "Yes, this family is struggling" or: "Yes, this child's needs are so complex that it is highly likely that this family will struggle" or it is an outside view that says: "This family really are struggling and we bring this to you as a professional to recognise and to take this forward."¹⁹⁵

The recent shortage of respite care due to the emergency family situations, combined with the "each case on its merits" approach to referral has created a situation where families are likely to reach breaking point before they are deemed eligible for respite care.¹⁹⁶ A Trustee of Autism Jersey speaking on behalf of their membership told the Panel that:

"It might be worth us sharing with you just very briefly what is the criteria for assessment if somebody needs respite. So we have lots of anecdotal reports and being told, mainly by social workers, that: "If you are about to kill yourself as a parent or your child is about to hurt themselves or seriously injure a sibling then we might be able to help you."¹⁹⁷

Furthermore, the Secretary of Autism Jersey told the Panel that members referred through CAMHS or an education setting for respite care have reported a similar experience:

"In the same respect you have also got within the education setting that when you go to get some support, perhaps from C.A.M.H.S. (Child and Adolescent Mental Health Service) or something similar, [parents have been asked]: "Has the child injured themselves? Have they hurt somebody else at school? Are they excluded? No. Come back when they do."¹⁹⁸

Autism Jersey also told Panel that some parents in their membership have been advised to call the police to deal with their child's behaviour management because *"once your child gets into the Criminal Justice System there may be a better chance of receiving some service."¹⁹⁹*

Key Finding: There is no evidence of formal criteria to assess a family's need for respite care, nor a written down Departmental policy with regard to how respite care should be accessed and delivered. Eligibility for respite is currently assessed through professional judgement and the severity of the family situation, which in times of respite shortage has meant that families are forced to breaking point to access services.

Recommendation: The Department should establish a) a formal policy outlining their approach to respite care and b) a set of detailed guidelines for professional 'gatekeepers' charged with assessment and referral.

¹⁹⁵ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.34

¹⁹⁶ Public Hearing with Autism Jersey, 2nd March 2012, p.28

¹⁹⁷ Public Hearing with Autism Jersey, 2nd March 2012, p.28

¹⁹⁸ Public Hearing with Autism Jersey, 2nd March 2012, p.28

¹⁹⁹ Public Hearing with Autism Jersey, 2nd March 2012, p.28

5.10 Poorly Communicated Services

Some parents told the Panel they had no idea that respite care services were available in Jersey.²⁰⁰ Others were frustrated that they were not given information sooner about respite care and how to access it. Mainly parents felt that communication about services was patchy, hard to get hold of and often contradictory.

According to the Service Director of Children's Services, the information about respite care is communicated "very well".²⁰¹ In the same statement, the Director said that Children's and Social Services are necessarily "discrete" and "subtle", and "you do not want to go shouting it from the rooftops."²⁰² He also told the Panel that "people know where we are...if people want to access any of our services we are in the phonebook, online, and all G.P.s know how to access our service."²⁰³

This statement identifies some problems with the way Children's Services is perceived internally and externally. The system appears totally preoccupied with not intruding into people's lives too much, but is actually externally perceived as failing to provide the kind of early intervention care which would prevent families going into crisis.

Key Finding: Information about what respite services are available and how to access them is minimal, hard to find and poorly signposted by professionals. The Panel was told that the Department seeks to avoid unnecessary intrusion into people's lives. However, this approach was felt to be a barrier to some families gaining access to services at an earlier stage.

Recommendation: The Department should develop a communications strategy to outline all the respite support services available to parents and how to access them. This information should be made freely available to all families caring for children with special needs, as well as being uploaded to the Gov.je website and disseminated to all health professionals, educational establishment and parent support groups.

5.11 Lack of social workers

Every parent who gave evidence to the Panel about Social Workers mentioned one of only two names each time. These two professionals were held in very high regard by parents who had worked with them, and the Panel were left in no doubt that they were doing an excellent job under very difficult circumstances. However, it seemed that there were too few Social Workers to go round based on the testimonies of witnesses. The Head teacher of Mont à l'Abbé told the Panel that professionals working with children with special needs were effectively "spinning plates"²⁰⁴ in terms of juggling the many demands of the community. In her opinion, "There are not enough resources to go round and although [all professionals at ground level] want to respond, and they get as frustrated as anyone else... there is not enough."²⁰⁵

Both Deputy Green and Senator Routier felt there was a lack of Social Workers available to support parents of special needs children, and were critical of the Department in failing to fund and resource additional posts.^{206 207} Senator Routier told the Panel that:

"...The Social Services Department, from my point of view, is under-resourced... I know when there was a need to assess every resident within Les Amis, they could not achieve that by themselves and they had to call in social workers from outside the Island to carry out an assessment of each of the residents. Assessments need to be done on a rolling

²⁰⁰ Focus group held at Mont à l'Abbé School, 22nd February 2012

²⁰¹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.10

²⁰² Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.10

²⁰³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.10

²⁰⁴ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.9-10

²⁰⁵ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.9-10

²⁰⁶ Public Hearing with Deputy Green, 28th February 2012, p.13

²⁰⁷ Public Hearing with Senator Routier, 28th February 2012, p.10

*basis. It is all very well saying: "Oh, we have done it once" and tick the box; it needs to be done continually because people's circumstances change all the time and their needs change. So there is, I believe, a need to increase provision of Social Services."*²⁰⁸

Parents complained to the Panel about the time it took to get access to a Social Worker, which was compounded by the subsequently lengthy referral processes:

*"We were informed that in order to get on the list for respite care we firstly needed a social worker, and go through a review process that could take up to six months, to see if we even qualify to receive some."*²⁰⁹

Though the Department was clear that anyone could "self-refer" themselves to Social Services, the Paediatrics Consultant told the Panel that without a named Social Worker on hand it was incredibly challenging to navigate the process of referral:

*"... [Self-referral] is one way to impede the potential for going forward because it means an active process of someone taking the time to say: "Okay, well I will go through the forms and the aspects of the information that social workers might require" without having a social worker right there and then saying: "Look, you do not need to do any referrals. I am here, I have heard the whole story. I know what is going on and I will process this. We will introduce ourselves to the family and carry on."*²¹⁰

He also highlighted that for some parents, stigma associated with going to Social Services also extended to Social Workers, making it even less likely that a parent would enter the referral process:

*"It is easier to come to a doctor or easier to go to a health visitor. It is a little bit more intimidating to go to a children's social worker."*²¹¹

Key Finding: Social Workers currently assigned to work with families of children with special needs are held in very high regard. However, there is a lack of Social Workers available to support those parents of children with special needs.

Recommendation: The Department should create at least 1 x additional full-time Social Worker post assigned specifically to children with special needs. Equally, additional Support Worker posts for this user group should be created to relieve the burden on Social Worker's workloads.

²⁰⁸ Public Hearing with Senator Routier, 28th February 2012, p.10

²⁰⁹ Written submission, 27th January 2012

²¹⁰ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.24

²¹¹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.24

6. Quality of Facilities

The Panel conducted site visits to Oakwell, Eden House and Maison Allo on two separate occasions, and spent a considerable amount of time interviewing Managers and staff members on their opinions of the physical state of the facilities. Each respite home faces a unique set of challenges based on the needs of the user group and the resources available, and in each case a number of successes and areas for improvement have been identified.

6.1 Oakwell

Evidence suggests that whilst Oakwell is currently providing a good service in terms of quality of care, the Panel felt that the facilities do not meet modern-day standards. During site visits, the Panel's attention was drawn toward a number of areas for concern regarding the structure and design of the current site, including:

1. Use of wallpaper and carpets in the home (which pose infection control risks)
2. Lack of wheelchair access from living room to outside
3. Shared bathroom facilities between two respite rooms in the new extension
4. Laundry facilities in the corridor next to two respite rooms and adjoining a staff office

The Health and Social Services Department has conflicting views on the state of Oakwell. The Service Director of Children's Services admits that there is need for "further investment" in the building and that it has been in use for "many years". Furthermore, the facility, which was built in the 1980's, has been described as "tired"²¹² and "outdated."²¹³ In response to the question of whether Oakwell needed to be refurbished or rebuilt, the Service Director of Children's Services said:

*"I mean I think if you look at any building you will probably do things differently. You are governed by the facilities that you have. The staff are using the facilities that they have there to the best of their ability."*²¹⁴

The Panel heard that the Department is planning a wider review of buildings in the Health and Social Services estate, Oakwell included. At the same time, however, the Director felt that Oakwell still currently met best practice for UK standards around children's care homes.²¹⁵ The Panel felt that they had not received a clear answer as to whether the Department intended to refurbish Oakwell or to build a brand new, purpose built respite home for children with severe multiple physical disabilities.

The Panel acknowledged that Departmental resources to create a "new Oakwell" were finite, but were surprised that there was little awareness of the considerable will expressed by third sector organisations to help fund such a project. In particular, Variety Club were receptive to the idea of helping potential support a project to refurbish or rebuild Oakwell. The representatives confirmed with the Panel that Variety do not identify needs or potential solutions to a problem, but rather provide the funding to make it happen.²¹⁶ They were very clear that they were a non-political, non-expert organisation and that their sole aim was to work with any partner to ensure that the needs of vulnerable children in Jersey are catered to.²¹⁷ The Chief Barker told the Panel that "Any child that needs help, we are here and that is why we raise the monies in this Island to be spent in this Island, purely for children."²¹⁸

²¹² Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 20

²¹³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 21

²¹⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 20

²¹⁵ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p. 11-12

²¹⁶ Public Hearing with Variety at Work, 29th February 2012, p.14-15

²¹⁷ Public Hearing with Variety at Work 29th February 2012, p.7-8

²¹⁸ Public Hearing with Variety at Work, 29th February 2012, p.7-8

Key Finding: Whilst Oakwell is currently providing a good service in terms of quality of care, the Panel is concerned that the physical environment fails to meet modern day standards.

Recommendation: The future of Oakwell should be decided in terms of refurbishing the current site, or constructing a new purpose-built facility in an alternative location in conjunction with the third sector. Any plans should take into account the rising demand for respite care.

6.2 Eden House

Whilst many parents were satisfied with the position and decor of Eden House, praising the fact that the home was discrete in terms of appearance, one witness with expertise in the provision of facilities for children with autism expressed concern that the building was not suitable for secondary age children:

“The staff [at Eden House] can only work with what they are given – a building that is not fit for purpose... No physical interventions (which are required when a child with ASC has gone into meltdown) can be carried out safely in Eden house as stairs and corridors are far too narrow therefore the staff are at risk as are the children if these interventions cannot be carried out as prescribed in training.”²¹⁹

During the course of its investigations, the Panel learned that Eden House is more suitable and appropriate for younger children with Autistic Spectrum Disorders (ASD), despite having recently accommodated adolescents. The Service Director for Children’s Services explained during the Hearing that the building creates challenges for providing care when children with ASD get older and physically bigger:

“Some of the conversations I have had, initially with staff, since taking over this service, show they feel it is more appropriate for younger children, and then as the kids get bigger and more challenging, then that building does provide a bit of a challenge for that. When there are difficulties, there are stairs, all of that. So, it is an issue that we are aware of.”²²⁰

The Department informed the Panel that Eden House is currently being refitted to align with the standards mentioned earlier, and of their intention to use an existing States property (Heathfield) as an additional location for long-term care for young adults with emotional and behavioural difficulties. According to the Department, Heathfield has larger and bigger corridors and is likely to be more appropriate for an older age group in terms of autism.²²¹ However, the Panel were keen to find out why Eden House had been constructed in a way that posed a risk to the health and safety of both residents and staff. An expert working in autism education explained that Eden House would not have passed UK inspection upon being built in 2004 according to Minimum Criteria laid down for Children’s Homes (Appendix 4). She highlighted to the Panel several areas in which risks associated with autistic young people had been ignored in the construction of the building, including the lack of fob key access to doors, the lack of visibility panels in doors, the narrowness of the corridors exacerbated by the size of the radiator covers, causing a further health and safety risk.²²²

When questioned as to why the initial design and subsequent construction of Eden House went against environmental guidelines for housing children and young adults with Autistic Spectrum Disorders, the Director for Adult Services admitted there had been an element of compromise in 2004 when the house was initially being built due to “limited resource”.²²³ He also suggested that a lack of knowledge in terms of appropriate living designs for people with autism had lead to oversights in the construction of for example, visibility panels in doors.²²⁴ The Panel noted that the

²¹⁹ Written Submission, Gay Waters, 21st January 2012

²²⁰ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 39

²²¹ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 39

²²² Public Hearing with Gay Waters, 2nd March 2012, p.15

²²³ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 41

²²⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p. 41

National Minimum Standards for Children's Homes which the expert referred to were published in 2002 and therefore would have been available to the Department and architects at the time of designing and building Eden House.

Key Finding: The Panel was advised that when Eden House was constructed in 2004, it would not have passed UK inspection according to the minimum criteria laid down for Children's Homes that relate specifically to health and safety criteria for children with Autistic Spectrum Disorders and emotional and behavioural difficulties. The current refurbishment aims to address these key issues. However, the building is only suitable for primary-school aged children, not the adolescent group that is currently using it.

Recommendation: Future residential developments for any group with special needs must take into account minimum environmental standards in the early planning stages. The health and safety of staff and residents should not be compromised by cost-cutting measures.

6.3 Adult Respite Facilities

At the time of writing, the Panel was waiting to hear confirmation from the Department as to whether the contract they currently hold with Highlands Luxury Care Home to provide adult respite has been reinstated.

The Panel conducted a site visit to Highlands Luxury Care Home in order to view the current respite provision purchased by Health and Social Services to provide respite for adults aged 18 years and over.

Concerns were raised by a number of parents which require further investigation by the Health and Social Services Department. These include emergency wheelchair access from the respite flat to outside, mixed-sex accommodation within a two-bedroom apartment with one shared bathroom and lounge, and an unmodified kitchen unit. Whilst the Panel accepts that many care homes in Jersey have similar features, it feels that in certain cases this is simply not appropriate.

One parent summarised their worry about Highlands Luxury Care Home in a letter to the Panel:

*"Since becoming 18, our child is now considered to be an adult and respite services had to move on. Our respite access is now via Highlands...which is essentially a nursing home for the elderly. Our child does not need nursing care and I don't feel that this is really an environment into which young adults should be integrated."*²²⁵

In response to questions about the suitability of Highlands Luxury Care Home to deliver young people's respite care, the Director of Adult Services told the Panel that a large part of the decision to contract Highlands Luxury Care Home in 2009 was based on the urgency of the circumstances facing Oakwell at that time, most notably in terms of young adults "bed-blocking" at the respite home and reducing respite for other families.²²⁶ Responding to further questioning about emergency access and the combination of young disabled residents living alongside older residents with dementia, the Director of Adult Services reassured the Panel that *"there was a very appropriate response given in terms of the registration requirements and the fire proceedings."*²²⁷

The Panel was concerned about the vulnerability of young adults with limited communication skills being placed in this kind of accommodation, and later questioned the Department again as to whether it felt that mixing young with old, physically disabled people with people with learning difficulties, and women with men in the same residential facility was "best practice". The Director of Adult Services told the Panel that it was not uncommon for this to happen²²⁸, but argued that the

²²⁵ Written Submission, 2nd February 2012

²²⁶ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.29

²²⁷ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.29

²²⁸ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.26

“uniqueness of a small island community surrounded by water” meant that in some cases compromises had to be made around the appropriateness of accommodating different types of residents in the same facility.²²⁹ He stated that *“people’s health and safety is not being compromised”* at Highlands Luxury Care Home, and that their physical wellbeing was also *“well looked after”*.²³⁰ The Director suggested that mixed sex/mixed ability accommodation was good for the residents in that it allowed them to broaden their horizons.²³¹

Key Finding: There are less adult respite facilities compared to children’s facilities, and those that exist sometimes compromise the wellbeing of the client to cope with the existing provision.

Recommendation: Risk management for adult respite services should be managed according to the needs of the individual rather than to the facility. Clients of differing abilities, ages and genders who are occupying the same residential area should be appropriately risk managed at all times.

²²⁹ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.26

²³⁰ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.26

²³¹ Public Hearing with the Minister for Health and Social Services, 12th March 2012, p.27

7. Quality of Care

7.1 Oakwell, Eden House and Maison Allo

The Panel heard high praise for the staff caring for children and young adults with disabilities. Parents' experiences of the care their children received at Oakwell, Eden House and Maison Allo were on the whole very positive:

*"The staff at Maison Allo are very supportive and professional. The fact that it is a normal house on a normal street makes the children and parents feel comfortable and consequently have a positive effect on all those involved. It is a very dignified service that Jersey can be proud of."*²³²

*"The service Oakwell provides and the care given to the children is exemplary and I know they try very hard to cater for my needs. The staff are brilliant with my son, taking him swimming, to the pictures etc, he is very happy staying there."*²³³

*"The staff from Eden house are brilliant and if it wasn't for them more children would be in meltdown."*²³⁴

However, the experience of Managers and professionals paints a different picture. In many cases the Panel felt that those providing the care were overstretched in attempting to keep up with demands from both families and Health and Social Services. The Head teacher of Mont à l'Abbé told the Panel that her staff often became outreach bank staff for respite providers at weekends, evenings and holidays because their skills were in such high demand.²³⁵ She was concerned that this would accelerate the risk of them burning out, especially since the majority of staff who worked for respite providers were those who support the most challenging youngsters at school, and were under even greater pressure than most.²³⁶ In her words, using Mont à l'Abbé staff to fill in gaps at respite care homes was "...a strategy, but in terms of the long term it is not really a good one."²³⁷

7.2 Highlands Luxury Care Home

During a Panel visit to Highlands Luxury Care Home, the Manager explained to the Panel that staff are equipped to deal with any kind of disability and the site itself is registered for all categories of care.²³⁸ He also said that his 45-strong staff are "multi-competent", and praised their ability to cater for both elderly clients and younger clients with a variety of special needs.²³⁹ He conceded that finding part-time staff was a challenge.²⁴⁰

Witnesses with older children pointed out that the care needs of a young person with (for example) cerebral palsy or autism are entirely different to that of an elderly person with dementia.

Key Finding: Parents highlighted the importance of continuity in terms of staff caring for their children. The Panel recognises the importance of having appropriately trained staff to care for children and young people with special needs in any setting – public or private.

²³² Written Submission, 3rd February 2012

²³³ Written Submission, 7th February 2012

²³⁴ Written Submission, 21st January 2012

²³⁵ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.13

²³⁶ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.13

²³⁷ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.13

²³⁸ File note, visit to Highlands Luxury Care Home, 2nd February 2012

²³⁹ File note, visit to Highlands Luxury Care Home, 2nd February 2012

²⁴⁰ File note, visit to Highlands Luxury Care Home, 2nd February 2012

8. Service Improvements

During the course of the review, the Panel identified a number of ways in which the issues facing the supply of respite care in Jersey could be addressed.

8.1 Short Term (6-12 months)

8.2 Increase Resources for Respite

The most pressing service improvement is to reinstate respite for regular users. Parents were clear about their immediate needs:

“In the short term we need the respite homes to be kept for respite; we need adequate outreach, if the worst happens.”²⁴¹

The Panel acknowledges that the Department is working to resolve the respite issues caused by the recent emergency situation, and is encouraged by the positive attitude of senior members of staff to getting the service back to normal as quickly as possible. In the meantime, increasing the amount of outreach respite would be greatly welcomed by many of the families struggling to cope with the minimal respite care currently available, and would help to cover the gaps in provision. This could be achieved in conjunction with the third sector, which has excellent knowledge about the needs of their memberships and resources available to deliver for example buddying services, advocacy services, support groups and so on.

As soon as the refurbishment is complete at Eden House, families who were previously receiving overnight stays should be contacted to arrange for this service to be reinstated. Any family who is not receiving any respite at all but feels they should be have been informed to contact the Director of Children’s Service to look at their individual case. If additional resources are required the Department should be ready to make the case for additional funding.

8.3 Secure Long-Term Care for Children Returning from UK Placements

The Panel learned that Heathfield is being considered as a potential site to house the children who are currently on placement in the UK, and plans are progressing ahead of their return in September. Another potential solution for long-term care has been identified in the form of a self-contained cottage adjoining Maison des Landes (a hotel that has been specially equipped for disabled users). The cottage is currently being refurbished, and will contain two self-catering flats on ground floor level which have their own separate entrance and staff flats on the floor above. The Director of Children’s Services has expressed an interest in viewing the finished flats in May, and confirmed that the Department is considering them as an alternative site²⁴² to house the two children with severe emotional and behavioural difficulties who are currently on placement in the UK.²⁴³ All options should be considered with a view to meeting both short and longer term requirements.

8.4 Increase Numbers of Social Workers

The Department must be prepared to recruit and appoint a number of additional Social Workers and Support Workers to supplement the work of the existing professionals assigned to children with special needs. It is not appropriate to have only two Social Workers operating in this area.

²⁴¹ Written Submission, 1st December 2011

²⁴² HSSD are also looking at Heathfield as a potential site for long term residential care, and have appointed an architect to draw up plans for 3 self-contained flats

²⁴³ File note from site visit to Maison Des Landes, 22nd March 2012

8.5 Publish Written Criteria and Guidelines

The Department as a matter of urgency should publish a written policy and criteria for access to respite services.

8.6 Re-brand Social Services

As the Minister has already identified, Social Services suffers from a negative reputation and tends to be associated with perceptions of failure, abuse and stigma. Changing the name of Social Services to Community Services would help to reduce some of the stigma associated with contacting the Service.

8.7 Recruit High-Level Foster Carers

The Panel feels that the Department should try again to recruit high-level foster carers, as a family-based care model is generally preferable to placing children in institutionalised care. The Panel understands that a recent recruitment drive to encourage people to provide foster care to young people with special needs had limited success. According to the Director of Children's Services this recruitment drive failed for a number of reasons: 1) because of tax issues with Social Security about how the professional foster carer would be identified, 2) because of particular socioeconomic factors unique to Jersey which preclude people stepping forward as foster carers.²⁴⁴ The Panel understands that the Department hopes to make another move into professional foster carer recruitment soon, and welcomes this commitment.

8.8 Improve Signposting

Alongside the re-branding of Community Services, the whole portfolio of services should be looked at with regard to how they are signposted by professionals. More information about respite care should be made publicly available on www.gov.je with an explanation about what it is for. A leaflet explaining the range of services available to parents of children with special needs (including respite care) should be made available at the point of diagnosis.

8.9 Clarify Information about Resources

The lack of comprehensive and detailed information on available financial and manpower resources is impeding service improvements. This must be addressed as a matter of urgency.

8.10 Medium Term (1-3 Years)

8.11 Secure a Dedicated Emergency Care Facility

The Department should prioritise identifying a site to provide emergency care in the medium term to meet current and future requirements. This would involve reviewing their 86-property strong portfolio and refurbishing an existing structure, or building from new. The Panel is aware that there are strict criteria for appropriate housing of Looked After Children, and any future development should take these into account prior to development.

8.12 Charitable funding to update facilities

The Panel identified considerable will amongst third sector organisations to fund the development of respite facilities or services. It would be logical to apply some of this funding to the most pressing issue surrounding facilities – that of updating Oakwell. Prior to this, the Department should ensure that the Coordinator of the Third Sector is tasked with identifying possible sums of money and funding opportunities for willing third sector organisations. It is important to build good relationships between the States and third sector if this is to be a viable option for refurbishing or rebuilding current respite care homes.

²⁴⁴ Public Hearing with the Minister for Health and Social Services, 27th February 2012, p.37

8.13 Intelligent Use of Resources

The Panel identified a number of circumstances in which resources that could benefit respite care users were being underused or not used at all. In particular, the Panel noted that one area in which parents felt there was not enough respite (at weekends) could be addressed by Social Services using the facilities such as those at Mont à l'Abbé School, which is well equipped for leisure activities. The Head teacher of Mont à l'Abbé School agreed and felt that if the facilities were "*staffed appropriately and safely*" by people trained to use the equipment there would be "*no reason*" it could not be used at weekends.²⁴⁵ In her view the problem with out-of-school-hours respite is "*...not about them having a place to have the respite, it is actually about having the trained, skilled staff to do it safely. I think if they have that then there is no reason why they could not use the school.*"²⁴⁶ Whilst the Panel recognises that it may not be ideal for children to attend their school premises on the weekend, it feels that this is better than no provision at all.

Furthermore she highlighted another issue that would prevent Mont à l'Abbé being used as a weekend respite day centre: parents having to drive their children to and from the school as well as being required to remain with the child during the activity, which in her view is "*not necessarily respite for the families.*"²⁴⁷ The Panel noted that Maison des Landes Hotel owns four wheelchair enabled minibuses which are not used during the winter, and are occasionally hired out to organisations such as Cheshire Homes to use for client transport.²⁴⁸ These minibuses could easily be used hired out to transport children to and from respite care services.

Maison des Landes was felt to be a missed opportunity by the Panel in terms of intelligent use of facilities for respite care services. The Hotel is entirely equipped to cater for the needs of people with all kinds of physical disabilities, and has specially adapted pools, beds, bathroom facilities and games rooms. Furthermore, it is in a quiet and peaceful location, and according to the Assistant Manager, is relatively underused.²⁴⁹ The Panel felt that there was scope to explore the possibility of hosting short breaks or other respite services at Maison des Landes, especially since the hotel is seeking extra business.²⁵⁰

8.14 Long Term (3-10 years)

8.15 Implement a Social Services Law

The Panel feels that in the long-term, the most important aim is to establish a Social Services Law which gives the States of Jersey powers to provide services in support of carers as well as placing a duty on the States to provide information, registers, policies and eligibility criteria surrounding access to respite care services. One example of similar legislation is the Social Services Act (2011) of the Isle of Man²⁵¹ which places a duty on the government to:

- gather information concerning persons in the Island who are in need of social care services or carer support;
- compile and maintain registers of persons in need of social care services or carer support in such form it considers appropriate;
- publish at such times and in such manner as it considers appropriate, general information about:
 - the criteria for eligibility for social care services and carer support under section 6 and in respect of any assessment under Part 2 or Part 3;
 - access to social care services and carer support; and

²⁴⁵ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.16-17

²⁴⁶ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.16-17

²⁴⁷ Public Hearing with Head teacher of Mont à l'Abbé School, 27th February 2012, p.16-17

²⁴⁸ Panel visit to Maison des Landes, 22nd March 2012

²⁴⁹ Panel visit to Maison des Landes, 22nd March 2012

²⁵⁰ Panel visit to Maison des Landes, 22nd March 2012

- the social care services and carer support provided or secured by the Department under this Act.²⁵²

8.16 Create an Advisory Council for Disabilities

In addition to this, it is important to establish an advisory body to provide guidance and advice to the States and Departments on matters relating to people with disabilities, and also to comment on current or future legislation to ensure the rights and welfare of this group are maintained. Again, the Isle of Man has such a body, known as the Tynwald Advisory Council for Disabilities. It is formed of 2 members of the local government and three individuals with expertise in working with disabled people, including one person with a disability, and has a statutory duty to give to any Isle of Man Government Department and Tynwald Statutory Board advice on matters relating to chronically sick or disabled persons and to recommend changes in legislation. The Advisory Council cannot enforce or give instruction, nor can it take up cases on behalf of individuals. Its role is to make recommendations, support and to ask questions on behalf of interested parties regarding general issues.²⁵³ The Panel feel this is a sensible model for Jersey to adopt in the long-term.

8.17 Adopt the Disability Discrimination Act and Children's Act

Ultimately, the States of Jersey must ensure that our legislation is in line with that of the UK as much as possible where vulnerable members of society are involved. To this end, the Panel recommends that adopting a Jersey equivalent of the Disability Discrimination Act must be the crucial goal to enshrine the rights of disabled children and adults in society. The Panel also believe that establishing a Children's Act, similar to that in the UK, is of the utmost importance to ensure that there is a clear social policy for the States' responsibilities with regard to children and young adults with a disability.

²⁵² Information accessed at <http://www.gov.im/lib/docs/infocentre/acts/2011/socialservicesact2011.pdf>

²⁵³ Information Accessed at <http://www.tacd.im/>

9. Conclusion

The Panel concludes that the respite care provision in Jersey for children and young adults is inadequate to meet the needs of the community, now and in the future. This is reflective of a systematic failure to invest in respite care facilities and services over the last two decades.

Since the Panel made it known that it was planning to undertake this review, Action for Children has been commissioned by the Health and Social Services Department to produce a report analysing the whole portfolio of Children's Services, including respite care provision. This report is due to be published in June 2012, and the Panel looks forward to seeing the fruits of this independent piece of work. The fact that two separate inquiries have been undertaken on this topic is a clear indication that there is an acknowledgement that vulnerable young people have been failed with respect to essential support services. It is the Panel's hope that the product of two public pieces of work will together help bring about the changes that the witnesses who gave evidence during this review so desperately asked for.

The Panel is very clear, however, that this report is not to be seen as a precursor to the Action for Children report, nor a duplication of work. This report has looked solely at respite care provision, and no other service other than passing reference. Importantly, this is a peer-lead piece of work which brings with it an understanding of the historical background to the current state of the respite care service. It has the power to convince, persuade, inform and hold to account those responsible for making decisions about the scope and shape of this vital service.

The Panel is pleased that the Minister has, on several occasions, welcomed the findings of this report as a means of helping to improve the current respite care service. The Panel is also grateful to the Minister and her Department for willingly providing a large amount of information about respite care and being open about the areas in which the service is currently failing. However, the Panel would urge the Minister to address the issues raised in this report and draw up an action plan to deliver the much needed improvements to the service.

The Panel is clear that more resources are urgently required to bring the respite care service into line with the expectations and needs of the community. The Department can no longer proceed under the philosophy of 'make do and mend' with what resources are available. Too many families have experienced extreme stress from a lack of respite care, and far too many families have been pushed into breakdown, divorce and ill health as a result. Respite care services should always be protected; this report opened with an evaluation of the evidence that confirms that regular respite is a sure protection against the negative consequences just mentioned. Authorities elsewhere recognise this, but Jersey has so far failed to protect its most vulnerable citizens by ring-fencing respite as a "must have" service that weathers even the most severe financial storms.

Respite care is not a luxury. It is an essential right of every parent and carer who spends 24 hours a day, 7 days a week caring for a loved one with a disability. The Panel is convinced that the welfare of a significant proportion of the population will be thrown into real doubt unless immediate action is taken to increase funding for facilities, staff and outreach. To act in any other way would surely bring into question whether Jersey really is a "truly civilised society."²⁵⁴

²⁵⁴ Peter Lodder QC, chairman of the Bar Council

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Review Hearings

The Panel held the following Hearings:

Public Hearings

Monday 27th February 2012

Session 1: Deputy A.E. Pryke, Minister for Health and Social Services

Tuesday 28th February 2012

Session 1: Deputy A.K.F. Green MBE

Session 2: Senator P.F. Routier MBE

Thursday 1st March 2012

Session 1: Ms. S. Auckland, Chairman, Variety at work

Friday 2nd March 2012

Session 1: Mrs G. Waters, retired Head teacher of residential School for autistic children

Session 2: Ms. S. Moore, Co-ordinator, Jersey Mencap

Monday 12th March 2012

Session 1: Deputy A.E. Pryke, Minister for Health and Social Services

Private Hearings

Tuesday 28th February 2012

Witness 1

Witness 2

Thursday 1st March 2012

Witness 3

Witness 4, 5 and 6 – accompanied by Deputy M. Tadier

Witness 7

Friday 2nd March 2012

Witness 8 - accompanied by Deputy M. Tadier

Written submissions

The Panel received the following written submissions:

- *MIND Jersey*
- Variety at Work
- Mrs G. Waters
- Head teacher, Mont à l'Abbé School

Panel Visits

The Panel made the following evidence-gathering visits:

Tuesday 13th December 2011

Oakwell House

Eden House

Maison Allo

Thursday 2nd February 2012

Highlands Luxury Care Home

Wednesday 29th February 2012

Oakwell House

Eden House

Maison Allo

Monday 12th March 2012

Aviemore

Les Amis and "The Lodge"

Thursday 22nd March 2012

Maison des Landes

11. Appendix

Appendix 1: Expert Adviser's Comment

I was appointed by the Scrutiny Panel in February 2012 to advise them on their review of respite care for children and young adults in Jersey. I joined them in Jersey for their week of scrutiny sessions from 27 February to 2 March. I was present for each of the scrutiny sessions during that week and played a part in questioning witnesses.

I also visited some of the Island's respite facilities and had the opportunity to contribute to the Panel's internal discussions on respite care. I was in Jersey again on 12 March and visited additional respite facilities with the Panel on that day. Since then, I have had the opportunity to comment on and contribute to drafts of the Panel's report.

Based on these activities, and on my previous experience, I believe that improvements to the system of respite care in Jersey need to be made in order to provide further support to carers of children and young adults with special needs. Most of the work of caring for these children and young adults is done, gladly, by their parents.

These parents need a relatively small amount of ongoing support in order to help them to continue to care successfully for their children. Better availability of high quality respite services would contribute to improving the quality of life of some of Jersey's most vulnerable residents and additional expenditure on respite services now is likely to mean lower expenditure in the future on addressing the negative consequences of insufficient respite for carers.

The high quality of care staff at respite facilities on Jersey, the positive attitudes of many parents and the fact that Jersey is a relatively wealthy society mean that Jersey is in a good position to move forward and develop excellent respite services for the future. I support the proposals for improving respite services in Jersey that are made by the Scrutiny Panel.

Siôn Jones
Partner at LE Wales

NEWS

A mother's plea for help

Parent of two autistic sons may have to put one in care

By Elaine Byrne

A MOTHER struggling to cope alone with her two autistic sons has made an emotional appeal for help through the JEP, and Social Services do not give her more support she will be forced to put her severely autistic son [redacted] into care.

The dental nurse from St Lawrence said that she was feeling like a prisoner in her own home.

[redacted] is severely autistic and has no sense of fear. His older brother suffers from mild Asperger's syndrome and has become a carer for his younger brother, who regularly self-harms, lashes out, bites and attacks his family.

Sick and tired

Mrs [redacted] said: "The last thing I want to do is put [redacted] into care, but I need more help."

She is sick and tired of broken promises' by Health and Social Services and is devastated that the budget for the already 'under-funded and over-resourced' psychology service has been slashed.

She has begged them for more support in managing her sons during the school holidays and wants to know why she was refused requests to take her older son away for a holiday in April.

"I enjoy my job and I don't want to become part of the Income Support burden or be forced to put [redacted] into care," she said.

During the holidays Mrs [redacted] plans to send [redacted] to a physiotherapist called the Freedom Activity Camp but its opening time at 9.15am causes real problems for her, because she has no support during the holidays. Mrs [redacted] who starts work an hour earlier as a dental nurse for the States, plans to leave [redacted] with her sister-in-law Victoria who already looks after five children - two of them also autistic.

People-carrier

She said: "[redacted] will bring [redacted] to me before she starts work, but I can't really bring him into the house with the five children because of his behaviour. So I plan to drive around the Island with all the children in my people-carrier for an hour until the physiotherapist opens. I shall do this every day for a week."

Mrs [redacted] said: "Why can't the States free someone up to arrange help for him? Unless I see 'I have had enough - I am not having him any more' they will not listen."

Health Minister Jim Pughard said that Mrs [redacted] received a regular short break through their services at Avonmore.

He explained that there were additional support in place to assist with the family first thing in the morning, with community-based staff helping to get [redacted] to school to allow his mother to maintain her current employment.

"The additional request is for an extended holiday break in April," he said. "However, we have said no to this, as we do not provide holiday breaks as a part of our core business. If we do, it limits upon the general provision of short breaks to other families. There have been occasions where a holiday break has been agreed and provided. However, this is usually due to exceptional circumstances due to the increased pressures on a family and their assessment of need."

• News Focus: Page 10.

Transcription of Text:

A mother struggling to cope alone with her two autistic sons has made an emotional appeal for help through the JEP. [Name redacted] fears that if Health and Social Services do not give her more support she will be forced to put her severely autistic son [name redacted] into care.

The dental nurse from St Lawrence said that she was feeling like a prisoner in her own home. [Name redacted]'s severely autistic and has no sense of fear. His older brother [name redacted] suffers from mild Asperger's syndrome and has become a carer for his younger brother, who regularly self-harms, lashes out, bites and attacks his family.

Mrs [name redacted] said: “The last thing I want to do is put [name redacted] into care, but I need more help.”

She is “sick and tired of broken promises” by Health and Social Services and is devastated that the budget for the already “underfunded and over resourced” psychology service has been slashed.

She has begged them for more support in managing her sons during the school holidays and wants to know why she was refused respite to take her older son away for a holiday in April.

“I enjoy my job and I don’t want to become part of the Income Support burden or be forced to put [name redacted] into care,” she said.

During the holidays, Mrs [name redacted] plans to send [name redacted] to a play scheme called the Freedom Activity Camp, but its opening time at 9.15am causes real problems for her.

Because she has no support during the holidays, Mrs [name redacted] who starts work an hour earlier as a dental nurse for the States, plans to leave [name redacted] with her sister-in-law [name redacted] who already looks after five children – two of them also autistic.

She said: “[Name redacted] will bring [name redacted] to me before she starts work, but I can’t really bring him into the house with the five children because of his behaviour. So I plan to drive around the Island with all the children in my people-carrier for an hour until the play scheme opens. I shall do this every day for a week.”

Mrs [name redacted] said: “Why can’t the States free someone up to arrange help for him? Unless I say “I have had enough – I am not having him any more” they will not listen.”

Health Minister Jim Perchard said that Mrs [name redacted] received a regular short break through their services at Aviemore.

He explained that there was additional support in place to assist the family first thing in the morning, with community-based staff helping to get [name redacted] to school to allow his mother to maintain her current employment.

“The additional request is for an extended holiday break in April,” he said. “However we have said no to this, as we do not provide holiday breaks as part of our core business. If we do, it impacts upon the general provision of short breaks to other families. There have been occasions where a holiday break has been agreed and provided. However, this is usually due to exceptional circumstances due to the increased pressures on a family and their assessment of need.”

Appendix 3: Breaks for Carers of Disabled Children Regulations 2011

STATUTORY INSTRUMENTS

2011 No. 707

CHILDREN AND YOUNG PERSONS, ENGLAND

The Breaks for Carers of Disabled Children Regulations 2011

Made - - - - 9th March 2011
Coming into force - - 1st April 2011

The Secretary of State for Education makes the following Regulations in exercise of the powers conferred by paragraph 6(2) of Schedule 2 to the Children Act 1989(a).

In accordance with section 104(3A) of that Act, a draft of these Regulations was laid before Parliament and approved by resolution of each House of Parliament.

Citation and commencement

1. These Regulations may be cited as the Breaks for Carers of Disabled Children Regulations 2011 and come into force on 1st April 2011.

Interpretation

2. In these Regulations—

“the 1989 Act” means the Children Act 1989;

“carer” means a person who provides care for a disabled child and who is—

(a) the child’s parent, or

(b) a person who is not the child’s parent but who has parental responsibility for that child;
and

“disabled” has the meaning given in section 17(11) of the 1989 Act(b).

Duty to make provision

3. In performing their duty under paragraph 6(1)(c) of Schedule 2 to the 1989 Act(c), a local authority must—

(a) 1989 c. 41. Paragraph 6(2) was inserted by section 25 of the Children and Young Persons Act 2008 (c. 23) (“the 2008 Act”). The power in paragraph 6(2) is expressed to be exercisable by the “appropriate national authority”. The “appropriate national authority” is defined in section 59(7) of the Children Act 1989 as meaning, in relation to England, the Secretary of State. Section 104(3A) was substituted by section 39 of, and Schedule 3 to, the 2008 Act and subsequently amended by S.I. 2009/1892.

(b) That is, that a child is disabled “if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed”.

(c) Paragraph 6(1)(c) (inserted by section 25 of the 2008 Act) requires local authorities to provide services designed to assist individuals who provide care for disabled children to continue to do so, or to do so more effectively, by giving them breaks from caring.

- (a) have regard to the needs of those carers who would be unable to continue to provide care unless breaks from caring were given to them; and
- (b) have regard to the needs of those carers who would be able to provide care for their disabled child more effectively if breaks from caring were given to them to allow them to—
 - (i) undertake education, training or any regular leisure activity,
 - (ii) meet the needs of other children in the family more effectively, or
 - (iii) carry out day to day tasks which they must perform in order to run their household.

Types of services which must be provided

4.—(1) In performing their duty under paragraph 6(1)(c) of Schedule 2 to the 1989 Act, a local authority must provide, so far as is reasonably practicable, a range of services which is sufficient to assist carers to continue to provide care or to do so more effectively.

(2) In particular, the local authority must provide, as appropriate, a range of—

- (a) day-time care in the homes of disabled children or elsewhere,
- (b) overnight care in the homes of disabled children or elsewhere,
- (c) educational or leisure activities for disabled children outside their homes, and
- (d) services available to assist carers in the evenings, at weekends and during the school holidays.

Short breaks services statement

5.—(1) A local authority must, by 1st October 2011, prepare a statement for carers in their area (a “short breaks services statement”) setting out details of—

- (a) the range of services provided in accordance with regulation 4,
- (b) any criteria by which eligibility for those services will be assessed, and
- (c) how the range of services is designed to meet the needs of carers in their area.

(2) The local authority must publish their short breaks services statement, including by placing a copy of the statement on their website.

(3) The local authority must keep their short breaks services statement under review and, where appropriate, revise the statement.

(4) In preparing and revising their statement, the local authority must have regard to the views of carers in their area.

9th March 2011

Sarah Teather
Minister of State
Department for Education

Appendix 4: States of Jersey Health and Social Services Eligibility Criteria for Respite Care

All children must be referred and assessed by the Social Work team before they can access respite.

Eden House

Who is eligible?

- Children who are on the **autism spectrum and/or with associated developmental complex needs**. Most children have associated challenging behaviour. There is no clear entry age but usually from 7yrs until 18yrs. (Best practice indicates that children should be supported at home in their early years).

Oakwell

Who is eligible?

- Children who have **physical disabilities, sensory disabilities, learning difficulties**. Children may have associated medical needs. Again there is no clear entry point but the exit age is 18yrs.

Appendix 5: Standard 10 from the UK National Minimum Criteria for Children's Homes (2002)

STANDARD 10 – Providing a suitable physical environment for the child

Underpinning Legislation:

Regulations: 31. Fitness of premises.

Outcome:

Children live in well designed, safe and pleasant homes with adequate space in a suitable location where there is access to the necessary facilities for a range of activities which will promote their development.

- 10.1 Each home is situated in a location that supports its aims and objectives and proposed models of care for children and young people. This includes children being able to access external services, recreational activities and to maintain and develop relationships with family and friends.
- 10.2 The home's location and design promotes children's health, safety and wellbeing and avoids factors such as excessive isolation and areas that present significant risks to children.
- 10.3 The home provides a comfortable and homely environment and is well maintained and decorated. Avoidable hazards are removed as is consistent with a domestic setting. Risk reduction does not lead to an institutional feel.
- 10.4 Physical restrictions on normal movement within or from the home are not used unless this is necessary to safeguard children and promote their welfare and development. Such measures are only used where agreed with the responsible authority and, if appropriate, the parents. Such restrictions for one child do not impose similar restrictions on other children.
- 10.5 For children's homes that are not secure children's homes, where specific measures, including electronic devices, are used to monitor children, there is a written policy that sets out how they should be used, how they promote the welfare of children, how children will be informed of their use, how legitimate privacy of children will be protected and how children will be protected from potential abuse of such measures.
- 10.6 Secure children's homes have emergency call systems that are effective in summoning staff assistance when needed.
- 10.7 Staff preparation and training cover health and safety issues. Staff are provided with written guidelines on their health and safety