STATES OF JERSEY



RESPITE CARE FOR ADULTS (S.R.4/2015): RESPONSE OF THE MINISTER FOR HEALTH AND SOCIAL SERVICES

Presented to the States on 22nd September 2015 by the Minister for Health and Social Services

STATES GREFFE

RESPITE CARE FOR ADULTS (S.R.4/2015): RESPONSE OF THE MINISTER FOR HEALTH AND SOCIAL SERVICES

Ministerial Response to: S.R.4/2015

Ministerial Response required by: 8th September 2015

Review title: Respite Care for Adults

Scrutiny Panel: Health and Social Security

INTRODUCTION

The Minister for Health and Social Services welcomes the Panel's report into Respite Care for Adults. The Minister is committed to ensuring that the needs of Islanders are met, in particular the needs of those most vulnerable in our society. Short breaks are an essential part of an individual's care package, and are important to provide a break for both the individual and their carer. The Minister recognises and applauds the role of carers, and is committed to supporting them where this is safe and affordable to do so.

FINDINGS

| | Findings | Comments |
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| 1 | There is no cohesive information regarding the breadth and depth of disability in Jersey. Information is held within different agencies including the Health and Social Services Department, primary care providers and the Social Security Department, but there is a lack of concrete data. Understanding the breadth and depth of disability in Jersey is a key element to developing a strategy; without it, services will not be tailored to meet people's needs and there will be an inability to plan for future demand. | The Social Policy Unit is currently conducting research into disability in Jersey, which will inform the development of a disability strategy in 2016. There are 2 phases to the research: 1. August – October 2015: In-house qualitative research, to provide an insight into people's lives and what it is like to live in Jersey with a disability, impairment or long-term condition 2. September – December 2015: A UK-based social research agency will undertake a Health and Life Opportunities survey in order to provide quantitative data on disability, impairments and long-term conditions in Jersey. The survey will be sent to a random sample of a quarter of all households on the Island (c. 10,000). This will provide us with a much deeper understanding of the breadth and depth of disability in Jersey. Following these 2 elements of research, further qualitative work will be used to help shape the strategy in Q1 2016. |

| | Findings | Comments | | | |
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| 2 | There are 11 respite beds in the children's service and 5 (which will decrease to 4 after July 2015) within adult services. There is a danger that users of the children's service will have insufficient facilities for overnight respite care when they reach 18 and enter into adult services. The disparity between children's and adult services may increase pressure on adult services and lead to over-reliance on out-reach and in-reach services. | hade tor children aged under 1/1 (for c. 1) | | | |
| 3 | Three residential beds in adult services are required to meet the demand for short break services for wheelchair users. From the end of July 2015, when Cheshire Homes will no longer provide such a respite bed, there will only be one respite bed which caters for wheelchair users. | Since Highlands ceased its short breaks in 2014, 2 beds have been available for adult wheelchair users. The bed at Jersey Cheshire Homes was fully utilised for longer-stay breaks, and the bed at Mourant Lodge was occupied on average for 100% of days. Therefore, it is assessed that 2 beds are sufficient for current demand. We are currently in discussion with Les Amis about adding an additional room at Maison Allo for non-ambulant users. This will bring the capacity back to 2. At the present time we are working with Silver Springs, which is assisting through the use of a non-ambulant bed within its facility. | | | |
| 4 | Evidence suggests that the need and demand by wheelchair users for respite will increase rather than diminish, with 3 more wheelchair users entering into adult services within the next 3 years. The Panel understands that there are several families waiting to access the wheelchair-friendly room at Mourant Lodge. It is also noted that | Maison Allo will include one room for wheelchair users; this will be available for the young adults who will enter adult services, and for those students at Mont à L'Abbé School who are eligible for short breaks and require wheelchair accessible facilities. HSSD has requested information on a number of occasions regarding the waiting-list for access to Mourant Lodge for service users, but has not been provided with this information as yet. However, data from Les Amis does indicate that the Mourant Lodge non-ambulant room has no | | | |

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| | there are a number of students at Mont à L'Abbé School who need physical support or have other mobility difficulties, and therefore are likely to require ground floor residential respite facilities when they enter into adult services. | spare capacity, which could be utilised by those eligible for the service. HSSD is currently providing additional capacity for non-ambulant adults through Silver Springs. |
| 5 | There is currently no spare capacity to cater for emergency cases. If a service user was to go into crisis, other users may have reduced access to residential short break services. | It is important that flexibility to respond to emergency needs is included. This can at times be a challenge, and is managed by social workers, working with families as their needs change. Data indicates that the existing beds are not being fully utilised – an average of 93% for Mourant Lodge and 42% for Maison Allo during Q2 2015. Therefore, there should be spare capacity for emergency short breaks within the existing bed numbers. Should a family go into crisis then Les Amis can (and do) open 'The Lodge' to assist in addressing unplanned respite need. It would not be value for money to hold beds empty in case of emergency short breaks needs; there will always be an element of operationally responding to needs as they can often change quickly. |
| 6 | Some families and carers have been left confused about the Long-Term Care Scheme and what it would mean for them in terms of respite care. The principle of giving people more "buying power" may lead to inequalities of distribution due to a lack of understanding about how the system works. | The Long-Term Care Scheme (LTCS) was introduced in July 2014. It includes support for adults living at home with some of their care being provided by a friend or relative. The support provided can include the cost of regular paid support and the cost of providing short breaks for the unpaid carer. This is a major new scheme, and both HSSD and SSD are working closely with families so that they fully understand the new benefit and can make choices as to how to receive care, including short breaks. At present, adults access short breaks through engaging with the C&SS Adult Short Break Co-ordinator or their assigned social worker (who will forward the request to the Adult Short Break Co-ordinator). In the future, adults will access additional short breaks through the same process, choosing to use |

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| | | their LTCS budget with a range of providers through the Approved Provider Framework. The Adult Short Break Co-ordinator will help individuals access the right care within the right location at the right time. |
| 7 | The Social Security Department has set respite care at 6 weeks for the year in relation to the Long- Term Care Scheme. However, there may not be sufficient overnight residential respite provision within Health and Social Services to allow for 6 weeks of respite care. This may lead to families having no other choice but to access out-reach and in-reach services. | SSD outline that each user can access short breaks up to a maximum of 6 weeks per year. Not all users need or want this level of care, nor will all of them qualify for it. Based on all known service users accessing the maximum 6 weeks per year, capacity and demand for 2016 would be: Adult and Young Adult beds – 2,880 days; demand up to 2,058 days (for c. 42 adults plus 7 individuals aged 14 and over); Children's beds – 2,500 days; demand up to 756 days based on 15 children aged 13 and under, plus 3 children aged 14–17 who access Oakwell. |
| 8 | More services are available within the children's service compared to adult services. For example, one of the respite homes within the children's service has a hydrotherapy pool facility. | Adults can access a wide range of services, from a range of providers, for example, Jersey Cheshire Homes provides access to its hydrotherapy suite to individuals using their LTCS funds. |
| 9 | No audit trail has been found of the decision to cancel plans for a new bespoke adult respite home. Evidence gathered during the review shows that there is and will continue to be a strong demand for this kind of respite care in Jersey. | There is a strong demand for both residential and out-reach short breaks, and it is important that safe, affordable services are available to meet this demand both now and into the future. The Commissioning Intentions demonstrated that there is sufficient capacity within the current services, and that existing providers are willing to continue providing services. Therefore, the significant cost of building a new facility can be avoided. |
| 10 | Home-based respite services (out-reach and in-reach) have developed more readily in recent years, whilst residential-based respite services have contracted. The Panel believes that these types of respite services should be additional for families | It is important that we provide choice for individuals, so both residential and out-reach services must be available. The States must meet the needs of individuals, but must be clear about eligibility for services and the amount of services that individuals can expect, in order to manage public finances. The Long-Term Care Scheme provides funding for eligible individuals, based on their assessed needs for paid care, unpaid care and short breaks. The individual will then choose |

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| | rather than a replacement for residential-based respite. | the package of care that they need and want, within their individual budget. |
| 11 | The previous Panel highlighted significant issues with the transition process in 2012. It appears that the process is still variable, and families and carers are still being left confused when their child reaches the age of 18. The Panel has been told that in order to provide an effective transition service, 2 additional social worker posts are required. | The 2 social worker posts have been included in the bid for funding for 2016 as part of MTFP 2. The service provision within Community and Social Services is currently being reviewed under the leadership of the newly appointed Managing Director, and the transitional needs of young people are a high priority. |
| 12 | The Le Geyt Centre is no longer fit for purpose as a day centre and does not have adequate facilities to meet the long-term needs of the service users. Plans have been developed for smaller bespoke premises to be provided around the Island with the Le Geyt Centre building becoming an autism centre. | Through LTCS, individuals will choose their own care package and services, tailored to their needs. The vision of Day Services is to move away from a traditional building-based service to one which provides improved daytime, community-based care as part of an individual's package. Community and Social Services and Jersey Property Holdings are working in partnership with Jersey Autism with the aim of developing an autism centre. |
| 13 | The transport provision to take service users to and from Le Geyt Centre is not working properly. Many of those most severely disabled spend a lot of time on the bus collecting other service users. Financial constraints have meant that there are no funds to replace the current vehicle which is in its ninth year in service. | Patient transport is currently being reviewed, with the aims of improving the service and reducing the length of time service users are on the bus. The current vehicle is listed for replacement within the next 12 months. |
| 14 | The States of Jersey does not have any statutory obligations to fund respite care for adults. As a result, services could be an easy | Whilst the States has not adopted specific legislation in respect of short breaks, the recent introduction of the LTCS has had a similar effect. The Long-Term Care Law provides a statutory entitlement to financial support for long-term |

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| | target for funding cuts, particularly in the current economic climate. | care costs for eligible adults – including short breaks where applicable. Benefit levels within the LTCS are dependent on the level of long-term care contributions collected from local residents and an annual grant provided from the Consolidated Fund. The level of the annual grant is set in legislation and is automatically uprated each year. Ongoing decisions as to the level of contributions and benefits will need to be taken by successive States Assemblies. |
| 15 | The Health and Social Services Department has proposed repurposing Maison Allo, currently a respite home which sits within the children's service, to a young person's facility for ages 14–21. Not only might this disadvantage children aged under 14, it also fails to address the residential-based respite needs for adults aged over 21. | The plan is to repurpose Maison Allo into a young adults' residential short breaks facility, which will provide continuity of care for those individuals who currently access this facility, who are aged 14–18, and who will soon transition into adulthood. Mourant Lodge will remain the residential short breaks facility for adults aged 18 and over. |
| 16 | The Health and Social Services Department plan to introduce eligibility criteria for those wanting to access adult respite services. Although eligibility criteria could ensure a transparent and consistent approach to allocating services, it should not mean that fewer families receive residential respite care, as the Panel considers residential-based respite care to be a crucial component in the service offered to families. | Short breaks are essential in ensuring individuals are able to live at home, providing a valuable break for the carers and the individuals alike. Both residential and out-reach short breaks will continue to be available. Eligibility criteria are needed for all Statesfunded services, in order to provide clarity about what individuals can expect to be publicly funded. These need to be set robustly, ensuring that the needs of individuals are supported. |

RECOMMENDATIONS

| | Recommendations | То | Accept/ Reject | Comments | Target date of action/ completion |
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| 1 | By the end of 2015, a framework for collecting and collating data and monitoring and developing performance within both children's and adults' services should be developed. This should be developed using data obtained from the Disability Strategy and in accordance with an information management system which complements collecting information from other Departments. | HSS | Accept (but with revised timescale) | Integrated reporting is incorporated as part of the HSSD Informatics Strategy. Where available, disability indicators can be included as relevant and appropriate. The Informatics Strategy also includes a plan to work across the Island to ensure that systems are in place and reports are produced appropriately. This will be discussed in the Islandwide Health and Social Care Informatics Forum. The Social Policy Unit is currently undertaking research work in the period to 31st December 2015. Any disability reporting framework will need to take account of the outcomes of this research, and of the strategy which the Social Policy Unit is planning to develop from Q2 2016. | 31.12.2016 |
| 2 | The Minister for Health and Social Services should ensure that overnight residential respite will continue to be provided to families and carers without having a negative impact on other services. In particular, the Minister should ensure that wheelchair users have sufficient facilities which the Panel considers should include 3 accessible beds. The Department should work in partnership with organisations such as Les Amis, who have offered to develop what is needed for families. | HSS | Accept | Analysis has demonstrated that 2 wheelchair accessible beds for adult residential short breaks are required. Discussions are well underway with Les Amis regarding this provision, and the Department will continue to work in partnership with Les Amis. In the meantime, one bed is available at Mourant Lodge, and one bed at Silver Springs. | 31.12.2015 for Maison Allo re- purposing and 2 non- ambulant beds at Les Amis |

| | Recommendations | То | Accept/ Reject | Comments | Target date of action/ completion |
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| 3 | The Panel was told that resources must be secured through the Medium Term Financial Plan 2016 – 2019 for 2 additional social worker posts if an efficient and effective transition service is to be provided. The Health and Social Services Department should develop new and innovative ways of working in order to provide an effective transition service within existing resources and not solely rely on securing funding for additional staff. | HSS | Accept | Funding for 2 Social Workers has been included within the MTFP 2 bid for Children's Services. We are also redesigning the Adult and Older Adult Services, with a view to improving services and value for money. | 31.12.2015 |
| 4 | By the end of 2015, the Minister for Health and Social Services should publish an update on the Carers' Strategy 2013 – 2016. This should include what progress has been made since it was drafted in 2013. | HSS | Accept | This work is underway, working with the Carers' Partnership Group. | 31.12.2015 |
| 5 | The Chief Minister, through his Assistant Chief Minister, should engage more closely with the Service User Forum and use it as an opportunity to develop policy, as it brings together people who have personal experience of multiple and complex problems. The Chief Minister's Department should publish formal records of the Service User Forum's meetings, which include specific actions to be taken forward. | CMD | Accept | The Assistant Chief Minister has recently commenced a review of the Service User Forum, including an assessment of its purpose, function and membership. As part of the review, consideration will be given to record-keeping and the potential publication of meeting notes. Any decision on whether or not to publish would be taken in consultation with members of the Forum (this includes individual service users who may or may not have reservations about publication). | November 2016 |

| | Recommendations | То | Accept/ Reject | Comments | Target date of action/ completion |
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| 6 | The Minister for Health and Social Services should ensure plans for the future of the Le Geyt Centre are fully costed before June 2016 when the second part of the Medium Term Financial Plan 2016 – 2019 will be lodged. The Panel also recommends that key decisions regarding this development are formally recorded and published so that service users are able to track its progress. | HSS | Accept | At present, Community and Social Services is reviewing day services and the future of the Le Geyt Centre. Providers such as Autism Jersey are being consulted, and once future plans are fully formed these will be consulted upon. The outcome of the consultation and any final decision will be formally recorded and published. | June 2016 |
| 7 | The Health and Social Services Department should investigate ways of providing a better transport service for users of day services, including working with the Voluntary and Community Sector. | HSS | Accept | Patient transport services are under review with the aim of improving service user experience. | June 2016 |
| 8 | The Minister for Health and Social Services should introduce a Social Services Law with Regulations and guidance to accompany the Law, to include a requirement to provide a break for carers and for individuals with disabilities in order to improve the quality of their lives. | HSS | Accept | The current draft list regarding amendments to legislation involving children includes Carers' Rights. Respite legislation could be considered within the development of the disability strategy, which is being developed by the Social Policy Unit in 2016. | 31.12.2016 |
| 9 | A "Care Navigator" will be employed for a short period by the Health and Social Services Department to work with carers to identify unmet needs and choose the most appropriate respite to meet all of their needs. The Panel's evidence suggests that support for carers in | HSS | Accept | Two Social Worker posts have been included in the bid for funding for 2016 as part of MTFP 2. The service provision within Community and Social Services is currently being reviewed under the leadership of the newly appointed Managing Director, and the transitional needs of young people are a | March 2016 |

| | Recommendations | То | Accept/ Reject | Comments | Target date of action/ completion |
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| | both the children's and adult services is required, and not just for a short period. | | | high priority. | |
| 10 | In order to ensure repurposing Maison Allo is the right approach, the issues identified by the Special Needs Advisory Panel (SNAP) should be fully addressed and answered in writing before plans for the facility are implemented. This formal response to SNAP's concerns should also be circulated to all service users of Maison Allo. | HSS | Accept | Members of SNAP have met both the Director of Children's Services and the Deputy Directors of System Redesign. SNAP has been asked to contribute to the redesign of respite care delivery to ensure that the voice of the service user is heard. | 30.09.2015 |
| 11 | The Health and Social Services Department should ensure that the eligibility criteria for accessing adult respite services are fair and consistent. Before finalising the criteria, the Health and Social Services Department should consult fully with the Special Needs Advisory Panel and other stakeholders. | HSS | Accept | Eligibility criteria are needed for all States-funded services, in order to provide clarity about what individuals can expect to be publicly funded. These need to be set robustly, ensuring that the needs of individuals are supported. The eligibility criteria for HSSD-funded adult short breaks services will be developed during the Autumn, and meetings will be held with stakeholders. Eligibility criteria are not needed for services for which individuals receive Long-Term Care Benefit, as the individuals decide which services they access, using their individual budgets. The individual budgets are based on need, following a robust assessment. | 31.12.2015 |

CONCLUSION

As the Panel recognises, work has been underway within the 2 Departments for some time; the Minister for Health and Social Services accepts all of the Panel's recommendations, subject to some minor amendments, and would be happy to share with the Panel the action plan which is being progressed. This includes ensuring service users and carers are involved in discussions, being mindful of the transition between childhood and adulthood, implementing the Long-Term Care Scheme for the breadth of an individual's needs, and ensuring that there are sufficient short breaks available to meet the assessed needs.