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Deputy Mary Le Hegarat
Health and Social Services Scrutiny Panel
BY EMAIL

1 September 2021

Dear Chair

Re: Respite Care for Children and Young People

The Panel has requested responses to six questions concerning respite care for children and young people.

May I clarify that under the Children (Jersey) Law 2002 [revised 2019] up to the age of 18 years of age (and up to the age of 25 years if they are care leavers) children and young people are the responsibility of Children, Young People, Education and Skills Service (CYPES).

Service transfer to Health and Community Services (HCS), for those assessed as eligible for adult services, occurs on the date of the young adult's 18th birthday (referred to hereafter as young adult / service user / individual).

This service transfer occurs through a planned process of transition coordinated and managed jointly by CYPES/HCS, but with CYPES leading principally. HCS is made aware of the young people on transition from age 12 years, with a formalised process occurring from 14 years. The CYPES Complex Needs Team works in partnership with the HCS Adult Social Care Team, and the CYPES Child & Adolescent Mental Health Service works in partnership with the Adult Mental Health Service.

Respite for young adults is provided from domiciliary and/or residential care providers in the private sector, and day services from HCS. Packages of care may have a range of Jersey Care Commission (JCC) registered providers to meet the assessed needs of an individual.

HCS provides essential day respite for young adults on the basis of assessed need from, and coordinated by, our JCC registered Le Geyt Day Services.

In terms of financial resource, adult services needs assessments are carried out by Adult Social Care and Adult Mental Health practitioners. The needs assessment feeds directly into Customer & Local Services (CLS) Resource Allocation System (RAS) to produce an Indicative Budget for Long-Term Care Benefit (LTC).

However, short break respite for adults (that includes young adults) is commissioned by HCS and provided at the Mourant Lodge premises, with staffing resourced from a number of private providers. This provision is for adults with learning disabilities and associated conditions. Currently a total of 21 adults, some of whom are young adults, access that service.

In 2020-21, COVID restrictions impacted respite service, with the backdrop of universal staff shortages compounded by only having one building-based (Mourant Lodge) respite service

available. This resulted in the need for more creativity with respite options, which has had a positive impact on choice. For example, 'staycations' using local hospitality services and linking with Jersey Tourism together with staffing from private sector providers which were selected by the service users and their families. HCS respite budgets paid for services, with invoicing for care provided at an hourly rate – effectively a pay as you go respite provision.

My responses are in relation to young adults who have transitioned to adult services and pertain to HCS provision. The Minister for Children and Education will provide a complementary response to your questions pertaining to respite (short breaks) for children.

1. *Do you believe that the current on-Island respite facilities available to children and young adults are utilised enough?*

- a. *A number of respondents expressed concern about the lack of an indoor 'base' for community outreach respite services, and the closure of Maison Allo for overnight respite care. What steps are you taking to review existing respite care facilities for children and young adults, to ensure they are fit for purpose?*

In terms of commenting on the matter of existing facilities being '*fit for purpose*', respite care for both children and adults comes under the auspices of the Regulation of Care (Jersey) Law 2014. It is the responsibility of the Jersey Care Commission to inspect respite care provided on the island. This applies to both private providers and HCS. Inspection reports are available for public viewing on the Jersey Care Commission website.

In relation to utilisation of on-island respite facilities, it is important to consider a personalised approach. Building based respite is one option. Rather than being building- /service-driven, and looking forward to the Jersey Care Model implementation, it would be desirable to have a range of options to choose from, and not just limit respite to being building-based. Some of those options, for example, could be outreach-based from the young adult's home, or the previously described 'staycation' style provision.

The aspiration would be for community assets to be tailored to afford more creative person-centred offers that are community-inclusive and promote life opportunities, alongside the young adults defining how they would like to spend their time and where from when receiving respite. Support wrapped around the person, rather than defined in relation to a building.

2. *Do you have a strategy in place to improve the retention and minimise turnover of staff employed to deliver respite care for children and young adults?*

- a. *The Panel understands that shortages of trained staff to deliver respite care services for children and young adults are being exacerbated by the current work permits scheme. Please can you advise what mitigations are in place to ensure non-British or Irish staff trained in the delivery of respite care, receive a valid work permit?*

I am informed that staff retention is good in Adult Social Care. There is neither an issue of staff turnover for adult services in general nor in particular for day respite.

In terms of 'commissioned respite', private providers are responsible for their own staffing needs.

3. Respondents often cited a lack of information about the respite care options available to children and young adults in Jersey. Please can you explain how information about respite care options is made available to service users?

CYPES and the Adult Social Care Team of HCS operate a 'Preparing for Adulthood Pathway' for young people in process of transitioning to adult services and involves their familial carers in the journey. The Pathway, derived from and implemented in the UK, commences at 14 years of age for relevant young people identified i.e. with ongoing social and health care needs that will extend into adult life as they begin their transition.

In the initial stages of the Pathway, the allocated Adult Social Worker attends periodic reviews that are led by CYPES. These meetings are the platform in which professionals, family and the young person discuss ongoing health and social care needs into adulthood and what aspirations and life goals they wish to achieve; this includes, but is not limited to, short breaks/ respite options, day services, housing, education, benefits (including Long-Term Care Benefit) and domiciliary provision.

In practice, HCS reports that parents differ in terms of how much information they want and at what stage. Some feel overwhelmed if they receive too much information at once, whilst others value this. The information that practitioners can impart is very restricted due to the limitations of the current offer of available respite care.

Officially at 18 years of age, the care coordination is taken over as a whole by HCS adult services.

4. In relation to overnight respite care options, the Panel understands that the only facility currently available for overnight respite care is operated by Les Amis. Do you believe that the Les Amis facility meets the demand for overnight respite care from young adults and provides enough options for their carers?

In keeping with the underpinning principles of the Jersey Care Model it is desirable to have a more personalised/person-centric approach to respite. At present, the only bed-based overnight respite service for adults is Mourant Lodge. I am informed that, on occasions, scheduled respite gets cancelled which can be due to staff shortages on the part of the provider. When this occurs, HCS looks at alternative provision and the respite may be in-reach, delivered in the person's home, rather than delivered as a bed-based service.

Personalisation means choice. For some young adults with more complex physical care needs, bed-based services are indeed required, and informal carers desperately require regular scheduled short breaks to maintain their caring roles. In its current form, families are receiving a service that is sufficient.

However, I also believe that with appropriate governance structures in place, families should be more in control of their resource allocation, to enable the young adults to access more meaningful respite.

There are many creative ways in which informal carers can be given essential breaks from their roles, whilst providing the young person with fantastic service provision that holistically meets their needs. An example of this is the 'staycation' described in the introduction. This style of provision has resulted in better outcomes and is in fact more cost effective.

It is prudent to challenge the mindset of believing we must continually invest in bed-based service provision. Young people should be offered life opportunities that enable them to flourish.

It is imperative that choice is afforded by expanding the range of options to support individuals and their families in the respite market moving forward.

5. Some respondents cited a lack of continuity transitioning from child to adult respite care services, causing unnecessary stress to service users. Please can you describe the current pathway for service users transitioning from child to adult respite care services?

Please refer to my response to Question 3 above, however, this is more for CYPES to answer.

However, from my perspective, respite provision from Eden House and Oakwell comes to an end when the young adult turns 18. The lack of a meaningful offers does cause frustration and upset for clients and their families, having been used to the structure and regularity of these services for children.

6. Do you believe greater involvement from regulated private sector respite care providers could improve the choice and availability of respite care options for children and young adults in Jersey?

The Jersey Care Commission is fundamental and vital in terms of governance, assurance, and standards in relation to the Regulation of Care (Jersey) Law 2014.

It is recognised that the Care Regulations could prevent different providers from working together, however, we feel this can be overcome. For example, dialogue would be welcomed on how provisions could be de-regulated, or amendments made to the discretionary conditions, to enable use of short-stay accommodation through tourism, resulting in any appropriate regulated provider with staffing capacity being able to commission the adapted property for the benefit of the service user. This in effect could give us additional space to offer a responsive needs-led pay-as-you go respite, which is less likely to be cancelled.

HCS has been considering future options for respite. Some ideas include:

- caring for individuals at home while family members take a break on-island
- trying to get social groups together to enjoy hotel events with low level support
- thinking about evenings out as respite and how we could utilise volunteer sectors to facilitate this change
- researching what has been happening in the UK and other jurisdictions to inform thinking.

HCS wants to be pivotal in supporting private care providers and in providing support such as skilling them up to provide excellent needs-led respite. HCS has facilitated a group forum for stakeholders from the care sector and Jersey Tourism (Simon Soare) to come together and formulate collaborative ideas to support the respite options for adults with Learning Disabilities.

Visits to sites have already taken place, such as to Chestnut Farm (Tutella Air BnB), Maison du Lac and the LIONS charity future development. Also, consideration has been given to “Respitility” at Les Ormes, The Radisson, The Merton Hotel, Liberation executive suites, and a number of self-catering apartments across the island to see how these facilities would best suit our respite service moving forward.

HCS staff have met briefly with Jersey Mencap and Les Amis to discuss the future use of Maison Allo with the aim of considering a pilot pay as you go respite option for more complex cases. This could allow interested individuals / families to book alongside a range of service providers and could potentially improve access to provide a more robust respite service. It is

felt this could be a timely option moving into winter, with the prospect of staff shortages and closure of existing respite options should Covid re-emerge. This could potentially be offered to adults, including younger adults.

It is recognised that those individuals with more complex needs are often the most difficult to support. However, being able to commission equipment and assistive technology to develop a wider choice of respite options for these individuals alongside co-production is more than possible.

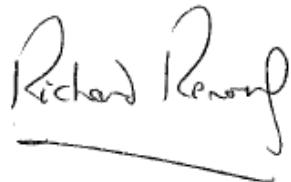
In concluding my response, I would also offer the following points for consideration.

In terms of Long-Term Care Benefit, respite is a free service to some, and this needs further thought and review. The lack of Long-Term Care Benefit funding can prohibit an individual's choice and scope. This can also slow the growth of the care providers in line with the Jersey Care Model. Working in partnership with our colleagues in CLS, and Users By Experience will help us to develop a much greater, more meaningful social care offer that puts the recipient of the service central and in control.

The Disability Strategy plays a major role in disseminating the needs of the community and I am sure will have some focus on essential respite. It is equally important to consider a Carer's Strategy.

There is a focus on gathering feedback from our service users. We recognise the need for User by Experience feedback to underpin and help to formulate a community needs analysis of what the future of respite needs to look like. We acknowledge this needs to be developed but some preliminary work in this regard is underway. The Learning Disability Cluster can assist us with data collection and service user family feedback.

Yours sincerely

A handwritten signature in black ink, appearing to read "Richard Renouf". Below the signature is a horizontal line.

Deputy Richard Renouf
Minister for Health and Social Services