Submissions – Respite Care for Children and Young Adults

Mark Jones

Thanks for the email and just to let you know my two handicapped children are still accessing overnight respite provided by Les Amis at Mourant Lodge, which i and them are happy with.

Regarding the points you raised:-

1. *The key challenge faced by parents is actually accessing the service and in a lot of cases this is down to the lack of social workers.*

   Furthermore there is continued advice given by civil servants and politicians that the the model of just offering short breaks, say 3 hours outreach, is what parents want however this is categorically untrue! I went to numerous meetings a few years ago to try and tell the ministers and civil servants that what they are offering is totally inadequate and if families don't get the right support this will create longer term issues.

   As expected nothing happened, instead we were quoted surveys carried out in the UK, and following those unsuccessful meetings, parents began to give up their fight for the proper support

   I'm an example of how important overnight respite is in getting families the much needed break

   My wife passed away in January 2012 and having a son with Downs Syndrome and a daughter who is severely autistic I would not be in the position I am today without the support of overnight respite

2. *Obviously not as the main children's overnight respite Maison Allo has ceased to provide support, and is presently empty when I know the demand from families is clear for all to see*

3. *See above re issues not being addressed .. still*

4. *None, I'll fully aware that from approximately 2016 to 2019 there were practically no referrals from Health to use overnight children's respite when there were lots of spare capacity*

5. *Obviously as the care providers are more aware of families needs due to their experience, however care providers are limited with want they can offer as they are not the ones controlling the purse strings*

In summary, it is the perennial problem of Health and their civil servants not listening to parents or having sufficient expertise in actually bringing up handicapped children and knowing how difficult it is

However, like most things that are wrong with government policy everything is dictated by financial restraints, hidden behind the position that they know best

In conclusion I'm so happy that my children are 29 and 24 years old as I would hate to fight for what I need with the states regime over the last 10 years

Should you need to contact me my landline is 734786.

Dr Tricia Tumelty, Executive Director Mind Jersey

Health and Social Security Scrutiny Panel- For the attention of Deputy Mary Le Hegarat

Respite Care for Children and Young Adults

1. ***In relation to the current Jersey respite care offering, what do you think are the key challenges faced by parents of disabled children and young adults in 2021?*** *In my responses I am assuming you are including mental health problems/mental illness in children and young people in definition of disabled… … but not sure as don't think young people who access services for their mental health conditions would see themselves as disabled..*

   Even prior to pandemic respite care had its challenges but now more than ever we need a clear mental health recovery plan for disabled children and their families. Disruption to education, care and support has had a huge impact of children young people and their families and has hampered their educational and social development. Many will have regressed in basic learning and life skills, and their mental health and wellbeing will have suffered. Many will have relied on support services outside of school, such as speech and language which may have been suspended at various times as we move through the pandemic.

   I understand that CYPES have another inclusion review established but it would be helpful for services and families to know what aspects of previous reviews over past decade have been implemented.

2. ***Do you think there are fewer limitations on access to respite care for children and young adults with a mental illness?*** *I am not aware of any respite provision for children and young adults with a mental illness. From what I can gather some children with serious mental health problem are admitted to Robin Ward at General Hospital and some other emergency placements but not spaces that are specifically designed to support and improve the mental health of children and young people*

3. ***Do you think that the current pathway for accessing respite care for children and young adults is more equitable, than the respite care offering in 2012?***

   Anecdotally I would presume yes but I have not seen any research with parents as to how the new changes to respite have improved things for children and families.

4. ***Do you think there are issues with the availability and /or stands of existing respite care facilities for disabled children and young adults on the island?*** *Yes and just completing this has made me consider how mental health /mental illness is defined or described in the respite provision documentation. And how children/young people and parents understand or describe the differences as well as the similarities.*

5. ***Please could you describe any positive developments in the provision of respite care for children and young adults in Jersey, that you have witnessed since 2012?*** *From what I understand more parents can now access respite care but I cannot comment on the quality of provision or availability of it*

6. ***Do you think that greater involvement by private sector respite care providers would improve the availability and choice of respite care in Jersey?*** *Yes but only if carefully commissioned /co-produced in partnership with children young people and families on the receiving end of services.*

Anonymous 1

I have read the letter provided and would comment as follows, although not to the questions specifically

*My comments made in 2012 around Highlands respite facility remain if this is still essentially a care home for the elderly, not the right place for young adults to be and not ideal for the existing residents either. I would have hoped by now that any fire safety issues have been addressed. I was not aware that this was still being used as a respite facility and would not be wanting **(Family Member)** to have respite there if at all possible.*

*From my point of view our current respite arrangements, whereby **(Family Member)** accesses Mourant Lodge, is perfect for her needs, it is homely and the staff are all very friendly, **(Family Member)** is happy to go there. **(Family Member)** friends also attend so this is a great place for her to meet up with them. The standards at Mourant Lodge fully meet **(Family Member)** needs.*

The key challenges faced I believe are the lack of available beds for wheelchair users as I understand there is only 1 which is at Mourant Lodge.

*All in all I am happy with our current arrangements, **(Family Member)** having overnight stays at Mourant Lodge, supplemented by the Services of All Care in our own home should we wish to have holidays*

Hope these comments help but if you require any further information, please let me know.

Anonymous 2

Thank you for the opportunity of giving feedback on Respite provision. We hope the information below will be of use to the Scrutiny Panel.

*About **(Stakeholder)***

Submissions – Respite Care for Children and Young Adults

(Stakeholder) *maintain a number of projects for adults with a learning disability ensuring our members have variety, choice and opportunity. For the sake of clarity, we are not a care provider, many of our members access our projects live independently- others live with parents and some have a variety of care packages ranging from a few hours per week to 24/7 care.*

(Stakeholder) *works closely with care agencies as many of their clients are also members of* ***(Stakeholder)****.*

Our projects include Taking Park Making Art (offering 6 art sessions per week), a buzzing social club and horticultural projects.

We welcome on average, 30-60 members at our activities each week.

Respite

As a charity, we have campaigned, supported and contributed financially to respite provision for many years. We regularly see how vital this is to parent-carers, siblings and our members.

Respite can help people with a learning disability develop more independence, skills, new interests a nd friendships outside of the family setting.

(Stakeholder) *bought a property in 2002 which was named Maison Allo. The house was purchased to provide quality accommodation for childrens respite. Les Amis have been the care provider offering respite from this property. In 2015, Les Amis requested a change of use from children to adult respite following a review with HSS. This was agreed with the proviso that should d mandcha nge in the future then it would revert to a children's respite property.*

In support of respite,no rent was charged for the use of Maison Allo up until 2019.

Since 2018 we have been aware of various issues surrounding respite provision at Maison Allo. Despite our best efforts we were unable to get to the root of the challenges as we knew families were very much in need of respite.

Currently, Maison Allo is not being used for Respite at all.

(Stakeholder) *are open to initiatives to utilise Maison Allo for the benefit of the Respite provision.*

Short-Break Respite

We were delighted to see the introduction of the short-break service in Jersey a nd recognise that this suits many families

There are concerns on how this might impact the much needed residential respite service and hope families continue to be offered both.

(Stakeholder) *Review of Respite in 2018*

In our efforts to understand the challenges surrounding respite we invited parent-carers to give us their feedback of their experiences. The results are compiled in the enclosed document which we presented to Minister of Health, Richard Renouf on 15th August 2018

Points of concern raised at that meeting were:

- *Families living so close to crisis point that it had become their norm.*
- *Lack of information for families- many unaware that respite might be available (in particular*

for families where English is not their first language).

- *Criteria set too high for some families to access.*

On 26th November 2018 at the ***(Stakeholder)*** *AGM we hosted a Respite seminar at Radisson Hotel*

bringing together staff from HSS, care providers and parent-carers . Our guest speaker was

Sarah Broadhurst, Principle Consultant from Oxford Brookes University. Sarah's presentation was following her many years research in the emotional journey of parent-carers and the impact of respite.

We welcome a full review of respite and raise the following concerns:

- *Residential respite- more is needed.*
- *How the introduction of Long Term Care Allowance will impact residential respite.*
- *The future use of Maison Allo.*
- *Communication of respite service to families who's English is not their first language.*
- *Criteria and application process to access respite.*
- *Reluctance of some families to speak up.*
- *Pride/Stigma "we're not in crisis", or not wanting to ask for help- Normalisation or grin and bear it attitude/or belief that only families at risk have respite.*

Anonymous 3

As I understand it, and I use Maison Allo in this the pathway for children to access respite is worse now than in 2012 Social Work referrals take too long, but I question how many referrals does children or adults with LD have to have, ie referrals at birth, referrals for social security assistance, referrals to get into Mont a L'Abbe school etc, so my comment is this....why another social worker referrals why can't any of the previous referrals suffice which would make access for respite so much easier and quicker.

The benefits for respite are immense in as much as "little Johnny" gets time away from his family to spend with his friends and to do something different. Mum and Dad and other family siblings get time for an evening or day together and have some quality time. Young adults with LD don't socialize in as much as they don't ring up their friends and say let's meet for a coffee in town....their socializing is via Mum and Dad other family members or ***(Stakeholder)*** *social group, but respite gives them the chance to meet their friends and from experience at Les Amis young people would get their friends to book respite at the same time and the spin off* *from this was they would form a group where they would start asking for the opportunity to live in the community together, ie house, flat.*

As regards the private sector I think this could be expensive and if clients need social work assessments then they will suffer the same long delays, but will benefits be cut if clients use the private sector!. I would remind everyone of Highlands in Bon Aire Lane, Four Seasons Group I think. Some years ago. They offered respite for adults with LD and people with profound difficulties, and I have to say they had great facilities. However, the take up was slow and they decided to move in OAP's to help cover running costs and it didn't work!! Would a private enterprise do the same thing to help with running costs! So this makes me certainly unsure of private sector involvement.

I think Public Health have a duty of care to our children adults with LD and respite should not be moved of their books after all the States find a lot of money for other things. and our clients get pushed to the bottom of the pile! It has taken some 9/10 years for the issue of respite to be addressed again and as I said before shameful.

These are my views

Anonymous 4

There is very limited overnight respite available for Children and young adults. It was very disappointing to see the loss of Maison Allo for children's respite. This was a fabulous facility loved by the children that used it but was unfortunately underused. The professionals kept saying there were no referrals coming through despite many families desperate for respite. The only facilities available for children now are Eden House and Oakwell which are being stretched to their limits. It appears that there is only Les Amis providing overnight residential respite for adults with very limited choices. There is no respite available for either children or adults for more than a night therefore families are not able to go away for a weekend or a week's break with their other children.

I believe that the standard of care varies considerably for both children and young adults. There is a constant change of staff within the different charities and care providers which is not ideal for our children and young adults who need continuity. Many are employed on zero-hour contracts or use the fact their management are disorganised and unappreciative for leaving their jobs. Depending which staff are on in the adult residential units will influence what, if any activities are provided for our young people - sometimes they don't leave the unit for the whole of their stay.

The development of the Short-term breaks for children provided by the Fostering department is very encouraging. Applicants have to apply, be assessed and then attend a panel resulting in a high standard of carers. We need a similar service to be provided for adults.

I think that greater involvement by private sector respite care providers would improve the availability and choice of respite care in Jersey. At the moment Les Amis have the monopoly regarding adult overnight respite. I also believe that if parents could be given an allowance to buy in their own respite this would give them the opportunity to select the right respite with the right provider for their child / young person. They could even pay family members or friends *who they know and trust to care for their loved ones. - this would also take the strain off the other care providers who don't always have enough staff.*

Anonymous 5

Challenges facing respite care are getting staff to stay in the care industry. I think they need to be valued for the work they do - Clients need continuity of staff Parents want somewhere like Mourant lodge, a small unit it makes it more personal.

We have continuity at the moment and I know most of the staff – for parents, this is really important. So I would say that has been positive Also no agency staff. They don't know the clients And the clients don't know them As for the private sector: New Horizons I know and feel my son would be looked after I'm not sure about other private sectors As long as they are all checked by inspectors And you could voice any concerns I think we could do with someone in the states to oversee the care industrie perhaps we might have one?

Anonymous 6

1. *lack of communication. I've been to respite meeting with les Amis which us parents was told gov health been invited and had reclined the meeting. I was told at meeting health had said only Mourant lodge needed for respite but health has told me it was a joint statement ? .who is being honest to us parents ? .as a single parent of young adult with disabilities .respite is important. it gives my son the chance to meet friends in a social place and to have a sleep over away from home.*

2. *no gone back wards I know covid and still is playing a part in our lives .but think more could be done to get back on track .the change of staff in the respite bookings* ***.(Member of Staff)*** *who has left was so understanding and helpful .was there any sort of handover done? They sent me an email asking for dates that i would like for respite and they say if we cannot do your dates we will speak to you about different respite .what does this mean ? .communication .*

3. *.yes issues with standards perhaps not providers' fault ? change of management and staff ? .and short of good trained staff to work with special needs young adults. My sons outreach providers are great and has helped him move on in adult life .but even they struggle to find enough good trained staff for special needs young adults.*

4. *i have had problems with respite since we left childrens service at oakwell.In those days, problems got sorted. I have said many times before that it feels like when my son became an adult they thought he had changed and can do what i can do but he still has the same disabilities as before becoming an adult but of course he has grown*

5. *as i understand, short of respite places to stay..*

Anonymous 7

1. *In relation to current respite care offering, what are the key challenges faced by parents of disabled children and young adults in 2021.*

- *The range of opportunities is very limited. There are only a small number of overnight respite options, and often families have difficulty accessing them for the hours or frequency that they require.*
- *When young people leave college their requirement for respite care often increases, however, this is often left very late to be organised, causing unnecessary stress.*
- *There is little provision made for those who cannot get themselves to their destination of choice, eg. Acorn, independently, but who’s parent is working and cannot make the journey.*
- *The lack of a designated base means that outreach in the community is very expensive business for families, eg. Paying for lunches, snacks, bowling, etc. If there was a “skills centre” base that could be accessed by the client and support staff, independence skills could be practised, sensory needs could be provided for and wet weather activities could be arranged.*
- *The options on offer to families and young people are not laid out early enough, the system is reactive rather than proactive in many situations.*
- *Transition to adulthood is very disjointed and brutal, eg. All the services change at the same time, both in health, social providers and education. Too much change is very stressful for a young person. Continuity in respite would ease this to some extent.*

2. *Do you think the current pathway for accessing respite care for disabled children and young adults is more equitable, than the respite care offering in 2012?*

3. *Do you think there are issues with the standards of existing respite care facilities for disabled children and young adults in Jersey?*
    - *The standard of individual outreach is very variable and does not always take in to account the personal programme of an individual, it is merely providing a “babysitting” service. When it is like this outreach support is not successful, no thought has been given to improving skills, or even maintaining those that school/college/families have worked so hard on. Driving around the island in the car, punctuated by expensive lunches in cafes, seems to be too often the tale for many sessions.*
    - *Again the lack of an indoor base is a serious detrimental factor in the quality of respite care.*
    - *There is little provision made for group activities amongst respite providers, 1:1 support is little value unless there are focussed objectives.*

4. *Please could you describe any positive developments in provision of respite care for children and young adults in Jersey, that you have witnessed since 2012*

5. *Do you think that greater involvement by private sector respite care providers would improve the availability and choice of respite care in Jersey?*

- *Potentially, yes. However, not if they are going to only provide the same service as current providers. Greater thought needs to go in to what services are provided and how the needs of an individual are catered for.*
- *1:1 community support is a very expensive way to provide respite if there are no discernible outcomes apart from keeping someone occupied out of the family home.*

Anonymous 8

"There still isn't enough respite care being offered to parents with disabled children or children with special needs, ie., Autism or ADHD. I am talking about the younger children up to the age of 16, which is our remit - I'm not sure what support is given to over 16s. But there always used to be a gap between the age of 16-20.

The facilities that are available could be utilised more. I don't believe that they are fully operational.

Whether this is due to lack of funding I'm not sure but Variety had put a lot of money into at least one of these homes and it is disappointing to hear that it's not being fully used.

It is very frustrating for the families as they feel that they aren't getting enough support and this reflects on the whole family.

I think that there definitely needs to be more support from the private sector. More professionals need to be employed to oversee the Respite Care and ensure the facilities are fully operational."

Anonymous 9

"Point number one, as a parent of a child on the autistic spectrum it puts a strain on the family ,you get angry with one another as you are exhausted and desperate for a break, also causes a strain having other children in the family and having to fight for support rather than it been offered .

Point 2 I have no experience with present respite care, however people I know say it is hard to get like it was when I went before scrutiny in 2012, it depends on who you get to see.

Point three yes we are sadly lacking support especially for Yong adults between 16 and 18, more should be done to teach life skills in the last two years at school cooking budgeting routines banking etc ,

point four there is more awareness but long waits on diagnoses and you have to fit between the lines to get it ,awareness is there just needs to be acted apon ,point five yes I think it's a great idea to give family's a choice of respite ,and providers , I would be happy to talk to the panel and meet yhem if requested, I would like to add when you talk about support my daughter was made to go before a medical board and answer questions about her disability's she is autistic diagnosed on level three by great ormand street under peditricancs at hospital ,the doctor on the panel just asked yes and no questions ,and I had to intervene ,as a result of this panel social reduced her from level three to two ,she got distressed about the panel,

and because of her condition which we belive has not improved lost £80 pound a week benefit ,this needs to be looked at making people with autisim or other issuses attend panels and except the specialist advise from hospitals .
Sorry about fathers mess of my original letter ,was getting a bit stressed when writing it ,as I have said I would like to go before panel if possible

Anonymous 10

We know, and have known from the earliest developments in community care, just how important it is for unpaid carers to have the opportunity of regular breaks from their caring responsibilities.

(Stakeholder) *have supported carers with breaks from their caring role through the provision of respite care. Research evidences powerfully how breaks from caring helps carers have a life of their own to the benefit of their own health and well-being.*

Following consultations that occurred in 2019/2020 ***(Stakeholder)*** *carried out a survey with existing service user families. The survey was shared with families and opened up discussion on what was required. Many of the families consulted have experience of both children's respite/short breaks and also adult provision.*

This consultation (May 2021) was to consider respite during Covid and beyond. It allowed families the opportunity to consider their own needs further, while also considering what was required for the future. Including funding (LTC or Block purchase) and the provision of a plurality of opportunities for breaks away from the caring role.

During the consultation meetings held on the 17th and 21st may, a small presentation was given looking at current research and areas for future research. Links have been established with one set of researchers for possible future work together.

From the consultation a number of recommendations arose:

- *Respite services work best when person-centred. They should be flexible to accommodate individual needs and circumstances, and to support personal choices and preferences.*
- *Families and Persons with disabilities need (accessible) information on respite services. The information provided should include respite models, local service information, service funding and allocation, policies and procedures. Information should include face to face meetings, opportunities for visits and experiential learning, easy to read information, videos etc.*
- *Service providers should engage with persons with disabilities, as well as their families, in relation to respite provision. In particular, service providers should consider the importance of compatible groupings and look at ways to engage with persons using respite services on this issue.*
- *Persons with disabilities should have the chance to influence the design and delivery of respite services if they wish. They may need specific supports to advocate for the respite services they need and want. Some individuals have limited lived experience of respite*

models and services and may find it hard to understand what a different service could look like.

- *Transitions between child and adult services should be easier to navigate.*
- *It would be helpful if approaches to respite provision could be underpinned by a national policy for respite in disability services as part of a community-based model of service provision and as an element on a continuum of support.*
- *Families felt that although there are other forms of short breaks, they advised that residential respite is valued and necessary. That residential respite should be available for extended stays weekends and longer periods. There should be opportunity for extending the day, especially at weekends.*
- *There was a strong sense that many people had not had the opportunity to experience residential respite. There was a retrospective necessity is accounts. Carers highlight the impact on their wellbeing and ability to cope only after receiving respite.*
- *New models for respite provision are emerging. These include supported hotel stays and in-home respite. Although useful, they should not be the only way of respite being provided and residential respite should remain.*
- *The introduction of personalised budgets is important, and there should be a variety of funding means for respite. Not every family wants to move to long-term care. It is important to consider how respite could be funded in the future, and how funding arrangements might support the development of quality respite services.*
- *Families were keen to have opportunity to meet and speak to policy makers, providers and commissioners.*