

Arrangements for Overnight Support for Children with Disabilities in Cambridgeshire

Parents and Carers Questionnaire

Summary of Feedback

June 2019

1. Background

This document is a summary of the responses to a questionnaire for parents and carers.

The questionnaire was sent to all parents and carers of children and young people who currently receive overnight support of some sort. It was also shared widely by Pinpoint, the SCIP information network, through other parent networks and on websites for any interested parents and carers to complete.

This summary has been collated by Siobhan MacBean (Cambridgeshire County Council) and Esther Harris (Pinpoint), who themed the free text comments from parents and carers.

The questionnaire was completed by 62 people.

2. Does your child have any overnight support outside the family home or paid overnight support at home at the moment?

Does your child have any overnight support outside the family home or paid overnight support at home at the moment?

	%	Number
Yes	73%	43
No	27%	16

If yes what type of support do they have? (NB not all answered this question)

Type of Support	Number
Residential outside the family home	16
In family home (using a direct payment)	6
Nurse led outside family home	9
Nurse led in family home	3
Other – self-funded, link foster carer, stay with other family, residential school	6

3. How old is your child

Age range	Number of children
Under 7	9
8 – 13	33
14 – 18	15
Over 18	2

4. How would you describe your child's disability and support needs?

There were a wide range of disabilities and support needs described by parents and carers and most included several issues in their response. The chart below shows the sort of things that were mentioned and how often. Due to the free text nature of this question it is not an exact list of the support needs but is summarised to give an indication of the things that parents and carers identify as the key issues related to their children's support needs.

Disability and Support Needs Described	Number of times mentioned
Autistic Spectrum Disorder	5
Severe Learning Disability	28
Complex medical and health needs of varying sorts	24
Life maintaining support and interventions needed	10
Physical disability	13
Sleep related support	8
Challenging behaviour	12
Support related to keeping the child safe	8
Mental health support needed	1
Palliative care	2
Constant, 24/7, full time, support/supervision needed	27

5. What is (or would be) important to you and your child for an overnight break?

The chart below is how parents and carers ranked from a list of what is important to them and their children.

	Order of importance
Safety of the child	1
Break for parents or carers	2
Happiness of the child	3
Child has fun	4
Meeting health needs	5
Break for brothers and sisters	6
Time for parents and carers to spend with other children	7
Location - where the overnight break takes place	8
The physical environment - what the place is like	9
Time for child to spend with friends or other young people	10
Learning opportunity for child	11
Preparing for adulthood, developing independence and experience of being away from family.	12

NB several parents commented that it's really hard to rank the things as they are all important.

These are some other things that parents and carers said were important to them. They are not in any priority order.

- Being able to book or arrange in advance
- Having several nights together
- For young person to have time away from the family with other people to get used to it as they will not always be able to live with family
- Trusting in people who will be caring for child – and trust that the needs will be met. Otherwise cannot relax and have a break
- Time for parents to recover and spend time with others to avoid isolation
- Continuity of care
- Reliability – not being cancelled
- Understanding and experience of working with children with complex needs
- Most important is that it's in own home

6. Which of the following is (or would be) your preference for an overnight break?

Parents and carers were able to select as many options as they wished

Type of overnight support		%	Number selecting this option
Overnight support in your child's home		37%	18
Overnight support with link foster carers in their home		31%	15
Direct payment workers to provide overnight support in their home		44%	21
Shared and longer term care (for those who may need more than a short break)		25%	12
Residential overnight in a short break children's home		70%	34
Other (see below):		27%	13

These are the other suggestions parents and carers made (in no particular order):

- Child goes on an organised trip/activity with an overnight stay
- Interim emergency support whilst waiting for more permanent solution
- Weekend availability at least twice a year
- Nurse led children's home
- Link with building adaptations needed
- Use childminders – they have already got their home set up to meet needs and know the child well
- Purpose built buildings
- Hospice like environment with open door policy to families
- Warm, friendly, capable and confident

7. General themes and views

The last questions asked about experiences of overnight support and any other views, thoughts or comments that parents and carers wanted to share. Esther Harris from pinpoint has themed these.

What's working

- Overwhelming number of comments on how respite is much needed
- DP didn't work, but overnight respite has worked.
- Prevents family breakdown – wouldn't cope without a break
- Some professionals understanding, empathy and hard work
- Quality time spent with other children
- LIFELINE

Frustrations/ Worries

Lack of understanding of processes and criteria = Feelings of disempowerment

- What is offered (short breaks duty statement is not always shared)
- Processes take too long
- Becoming and finding a LINK carer
- Frustrations round who can be a PA
- Misinformation/not communicating offer and what level their child has been put at
- As above. MH and 'higher functioning' autism have to be seen for the hugely disabling conditions that they can be, and support has to be given to families who struggle to get it, because they look like they're 'coping'. Too many people are shouting out for help, and being left in untenable situations.

Provision

- Want to rely on staff, but don't feel able/safety issues
- Appropriateness of provision, specifically children/YA with complex needs
- Quality of care an issue
- Cancellations
- Medicines protocols not adhered to, or misinterpreted
- Lack of good behaviour management of all children
- Child not being able to have breaks with friends
- Cancellations (some half of what families were offered)
- Transport issues
- Feel pressured to have residential care

Experience

- Fight to get provision
- Never offered, never explored
- High turnover of staff

Ideas for improvements

- More staff needed at residential homes
- More understanding/training needed to be effective staff/PAs
- Want DP workers to provide their home as overnight respite
- Care in own home
- To allocate certain amount of nights a year per family and let them plan how they want to use it.
- To offer less amount of overnight stays per family, but to cover a wider range of families - this would provide a break for family and prevent overtiredness and help family with excessive stress. This would bring some life balance for other siblings, and give a much needed rest for carers
- There could be more organised fun activities trips for YP with overnight stay to give them chance to learn and develop independent skills. This would provide a nice option for family, when the cares feel their child have enjoyable time and less guilty when the child spends a night from home.
- Care needs to be flexible and bespoke
- Better informed social workers needed
- Speed up processes

Questions/issues to clear up

- What is panel? How does it work?

Main points

- Trust between parents and support workers/residential provision
- Provision not flexible or wide-ranging enough
- Consider offering overnight respite in private homes – families and their DP worker
- Can't stress enough how important getting the offer to parents right
- Importance to stress again that it's not a cost-cutting exercise
- It works when everyone is engaged and the family are in control

Some Quotes

- “The lack of overnight respite and short breaks available is extremely damaging to parents and carers. It must be recognised that not having this provision is not sustainable and needs to be met ASAP. Everything is a fight and a struggle and it's extremely debilitating to not have any form of respite.”
- “I think it is fantastic you are carrying out this consultation and it's about time! I know too many families of children with the highest level of physical disability and complex medical needs who are not able to access any overnight care while children with lesser medical needs are more easily able to access care. I know many families being pushed to the edge of what they can cope with and battling mental health problems as a result. Children are living in the community with increasingly complex medical needs and parents are providing increasingly complex medical care in the home with no break! Change is overdue, as shown by the fact it's taken us 2-3 years to secure safe and appropriate overnight care for our son.”
- “I would like a pack made up of the types of respite available for all families so families don't need to ask it's all there for them sometimes it's hard to admit that you need a little helping hand or extra support especially overnight care. You don't ever know what's actually available to you or your family”
- “We need more respite, we need decent, passionate, engaged staff, who are permanent employees. This will bring all the other things that we need. Nearer home”

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