

Experiences report: Special Educational Needs and Disability services

Purpose

1. This report informs the Board about the experiences of families and children and young people with special educational needs and disabilities during the pandemic.

Background

2. Over the course of the past two years we have received feedback from families and partner organisations working with families that they are struggling to get the help they need. The impact on children with disabilities and their families is increasing as time goes on.
3. This report summarises the experiences that we have been told about. It is concerning that the families with least resources will be impacted the most.
4. Paragraphs 17 to 19 summarises parents' experiences. What parents say would help them is set out in paragraph 20.
5. The information set out in this report has been reported to the CCG Harm Review Group. The findings from this review are being considered and will be escalated to the CCG Integrated Performance and Assurance Committee. But it is, as yet unclear what action will be taken.
6. We would like to thank the families for telling their stories and for Pinpoint, Family Voice and Little Miracles for helping get those stories heard.

Action required by the Board

7. The Board is asked to:
 - Note the report.

Author

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Little Miracles

8. Little Miracles is a Peterborough-based charity that supports families that have children with additional needs, disabilities and life limiting conditions. Little Miracles have been told by families that:
 - People feel like they have become reduced to numbers, unseen and those who need support most of all feel abandoned
 - Families have had to cope with what has been the hardest year ever without their normal resources and support
 - Families report lots of people asking them the problems but many feel people have not listened to them or been able to roll up their sleeves and help
 - People are still feeling very scared and isolated
 - Families feel like they do not meet the criteria for support and feel pushed to crisis point in order to get help.
 - More and more families are relying on charitable support

9. Families told Little Miracles that the impact of isolation and withdrawing from society and support has left them exhausted and in poor mental health. Many families report facing financial disaster.

10. What families say would help:
 - 'Our children are children first with hopes and dreams please do not see them as a number, a financial drain or a burden.
 - We want to work with you as equal partners not against you, you are the expert in your field we are the experts in our children
 - Services need to communicate better with ourselves and each other it should not be up to families to need to chase this
 - If there are long waiting times to be told this - and to know what can we access in the meantime
 - To know about support available (including charitable support)
 - Clear referral pathways and criteria so we know where we stand.
 - Basic facilities in place (e.g. changing places so our children can use the toilet when they visit you)
 - Support and respite - it is not acceptable for families to have to reach crisis point before being offered support.
 - If you do not know the answer please be honest and tell us so we can find out together'.

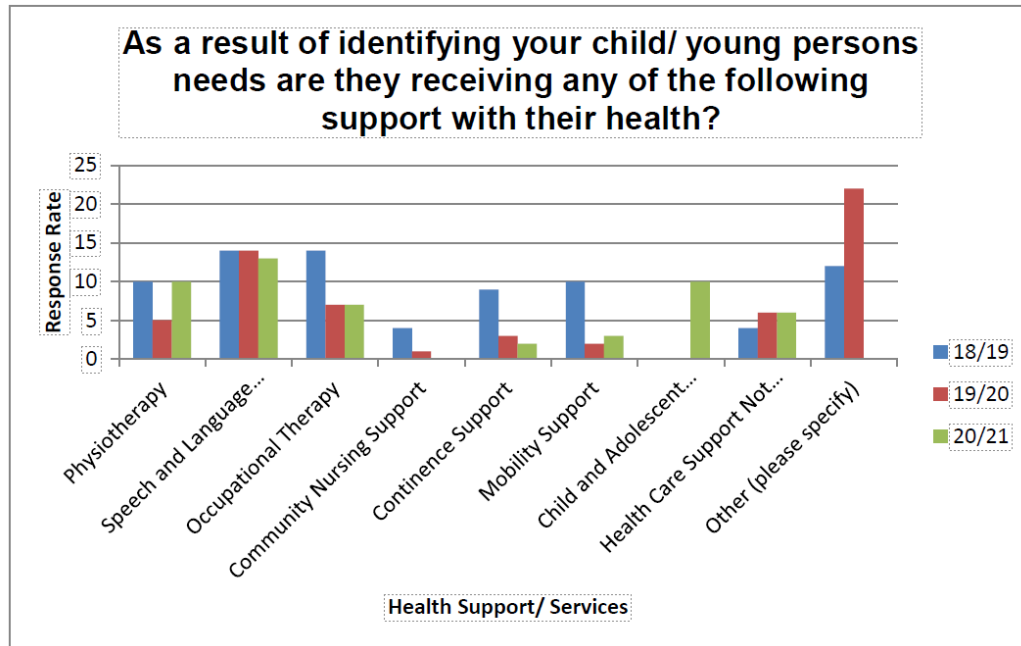
Pinpoint

11. Pinpoint is the Cambridgeshire statutory parent-carer forum, supporting parents who are caring for children with additional needs. Over the past two years families have told Pinpoint how they are struggling to look after children with additional needs.
12. 59% of parents responding to the Pinpoint 2021 annual survey said that the support they received from health services was good, with 15% being very good. 41% reported that support was not very good. Pinpoint note that it was a small number of parents who responded. Families say that they have been seriously impacted by Covid; they are fatigued, struggling, have little capacity and too much else to contend with.
13. There are some of the quotes from parents:
 - Accessing support for mental health has been challenging
 - The coordination of complex care across these services is failing
 - Carers find themselves repeatedly highlighting needs to separate services when a holistic approach would help
 - I did a parent led EHCNA (Education health and care needs assessment). All assessment were paid for by me. We have had no health assessment from health services.
 - We have struggled to get help from CAMH (18 months from a referral to a diagnosis and still awaiting an appointment to discuss medication some 24 months on!).

Family Voice

14. Family Voice are the Peterborough statutory parent-carer forum, supporting parents who are caring for children with additional needs.
15. The Family Voice annual survey for 2021 showed similar findings to that of Pinpoint. In the survey parents told Family Voice that:
 - (It has) taken a LONG time to get support, still chasing our tails to get the right team to speak to us.
 - GP refused umpteen times to refer for diagnosis. Neurodevelopment team refused 3 times now over the years to assess despite private assessment which identifies possible ADHD and suggested local diagnosis.
 - (There is) inadequate provision for mental health issues that aren't life threatening.

16. This graph summarises parent carer responses to the Family Voice annual survey.



Summary of experiences

17. It is clear that parents highly value the hard work and commitment of NHS and social care staff.

18. However, there are very large areas that need improving if the experience of parent-carers is going to improve. Parents say that there is:

- There is a ‘tsunami’ of unmet need
- Poor parent carer resilience
- Poor professional resilience
- Need to triage better earlier
- Lack of system resource including professionals
- Increase in economic, physical and emotional pressures.

19. Parent-carers are clearly under severe strain. The risk of more family breakdown is real and increasing, the consequences of which could well mean that children need to be cared for by the local authorities.

What would make things better

20. Parent-carers have highlighted the following as areas of improvement that would make a difference and help them continue caring for their children:

- Clear pathways, possibly presented visually, that are easily understood and that work every time
- More system capacity
- Single point of entry
- There should be choice in the way that services are accessed, ie online, telephone, face to face
- More comms to explain new service delivery models.