Cumbria Early Intervention Pilot

Family-carer survey

Contents

Summary

As part of the Cumbria Early Intervention pilot we developed a survey for family carers of children and young people age 0-25 with a learning disability or autism whose behaviours challenge living in Cumbria. The survey was circulated via a range of local networks and was open from 14 December 2018-25 February 2019. The number of respondents was lower than hoped; 38 family carers responded. This is around 4% of the total number of children with an Education, Health and Care plan in Cumbria (although this statistic does not correlate directly with the target group it is the best proxy we could identify.) The survey results should therefore be read with caution, in the context of a small sample size, which may not be fully representative of the broader population. However, they do point to some clear messages, which we believe merit further exploration by the region. These include:

- How to provide better **local information and support to families** bringing up a child with learning disabilities or autism whose behaviours challenge. Over 50% of the families responding to the survey reported challenging behaviour from their child on a daily basis. 75% of respondents said they wanted more information about supporting a child who displays challenging behaviour and 75% about services that could support them.
- Further exploration of **unmet health needs (both physical and mental health)** among children with learning disabilities or autism in Cumbria. Concerningly, 50% of respondents to this survey who tried to access Paediatric care for their child were unable to do so and 35% were unable to access mental health support. Almost half were unaware of how to get a referral to health services they may need for their child.
- Exploration of how to **involve families in co-production** of the delivery of the NHS Long Term Plan commitments for children with learning disabilities and autism; potentially building on the SEND infrastructure. A majority of respondents were aware of the Local Offer, the Parent Carer Forum and SENDIASS, yet 80% were unaware of Transforming Care, with only one respondent having any involvement.
- **How to best secure the views of families in the future:** we don't know why the response rate was low. We do know that this is a hard to reach group of families who are often isolated and not connected to networks. We subsequently discovered that a North East and Cumbria Transforming Care survey was open at the same time and although the response rate was fairly good overall, it was very low for Cumbria. This suggests there is a wider engagement issue that needs to be addressed. Families whose children challenge might not be in touch with the local networks through which the survey was distributed. Even if families were aware of the survey, other priorities/ time pressures and lack of confidence that it would deliver change may have discouraged them from inputting. There needs to be investment in families to help understand the best ways to secure future engagement.

Method

This survey was developed by the Challenging Behaviour Foundation to seek the views of families with children age 0-25 in Cumbria with a learning disability or autism and behaviours described as challenging. It was informed by the findings of the national Early Intervention

Project and the two focus groups held with families in Cumbria in June and October 2018. The feedback from these helped to inform the issues covered.

The draft survey was reviewed by the evaluator of the Cumbria Early Intervention Project, the Steering Group for the project and a family-carer who has been key to the Cumbria Early Intervention Project. Changes were made to reflect comments; in particular, shortening the survey by removing some sections (in response to evaluator comments) and adding a question on unmet health needs (in response to family-carer comments). The final set of survey questions can be seen in Appendix A. The survey was anonymous but respondents were invited to give their contact details separately for the chance to enter into a draw to receive a £25 Amazon voucher if they completed the survey.

The survey opened on 14 December 2018 in survey monkey format, so it could be completed online, on a computer, tablet or phone. A link to the survey was sent to the following groups by the Challenging Behaviour Foundation, with a request to disseminate on to family-carers.

- The Cumbria Challenging Behaviour Facebook group
- Cumbria Early Intervention project Steering group members
- Cumbria special needs groups
- Carlisle Mencap
- Cumbria Parent Carer Forum
- Those families who attended the two focus groups

The online SurveyMonkey survey was due to close at the end of January. A reminder was sent out to groups listed above on 14 January, asking them to remind families they were in touch with to complete the survey. At the end of January there were 35 responses. The Challenging Behaviour Foundation decided to extend the deadline to 25 February and contacted all those listed above to send a “final chance” email to families, reminding them that this was a chance to have their say and the potential to win the Amazon voucher.) The survey closed on 25 February, at which point it had been completed by 38 individuals.

Survey findings

Location

(Source: Google maps)

The red markers show where respondents live. If more than one respondent gave the same postcode only one marker is shown. LA14 and LA9 were the locations with most responses.

The majority of responses were from South Cumbria (62%), with 35% of respondents living in West Cumbria and just 3% of responses from North Cumbria.

Information about the child

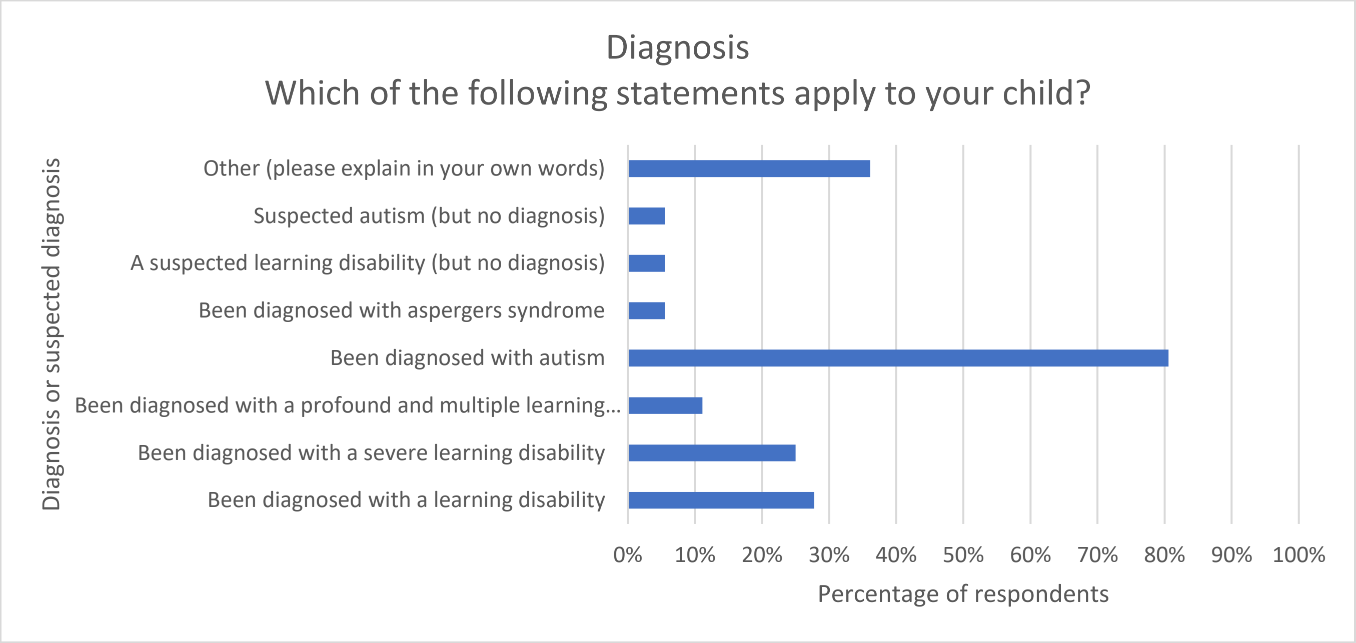
Respondents to the survey had children aged between 3 and 22 years. 91% of the children in the survey lived at home.

Diagnosis

Respondents were asked about diagnoses that applied to their child. 80% of respondents said that their child had been diagnosed with autism. 28% said their child had been diagnosed with a learning disability, and 25% had been diagnosed with a severe learning disability. Half of those whose child had been diagnosed with a learning disability also answered to say their child had been diagnosed with a severe learning disability. 70% of those diagnosed with a learning disability also had a diagnosis of autism.

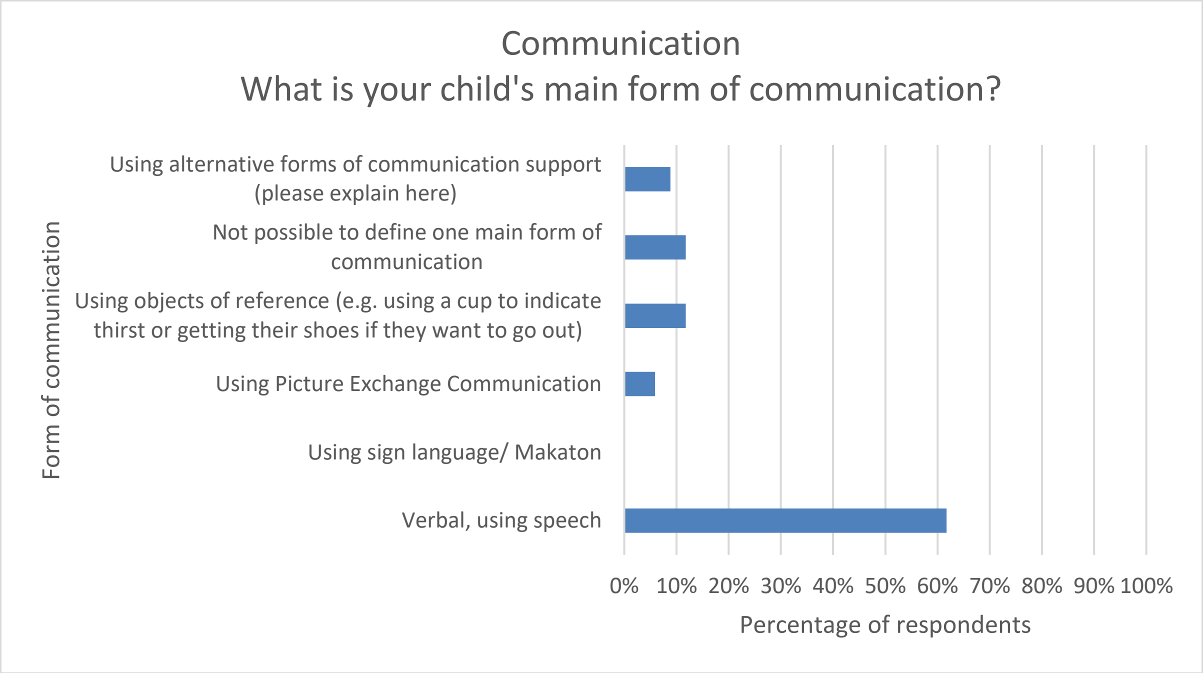
36% chose ‘other’ listing the following (among others)

- Anxiety disorder
- PDA suspicion
- Profound autism with severe learning difficulties
- Down Syndrome
- Extreme OCD



Communication

For 62% of respondents, their child's main form of communication was verbal, using speech. Therefore, for 38% of respondents speech was not the main form of communication for their child. 11% of respondents said their child used objects of reference as their main form of communication and 6% used picture exchange communication.



11% of respondents said it was not possible to identify one main form of communication for their child. Other alternative forms of communication include gesture, noises, and body movement.

Hopes and ambitions

Survey respondents were asked an open question about their hopes and ambitions for their child. Happiness was a common hope/ ambition, appearing in just over half (19) of the responses. Education and employment also both emerged as common themes across the answers. Communication was mentioned in 14% (5) responses. Overall families had high and positive aspirations for their child.

Happiness

"Happy healthy and anxiety free!"

"Happy, healthy, fulfilled life, independent as possible."

"To be healthy, happy and safe"

Education

"to grow up well and healthy, be able to attend school"

"To get an education." "To go on to study in HE…"

Employment

"To become an independent and economically active adult, likely needing support to live and work"

Communication

"To increase her communication and independence."

"communication is all we dream of"

Barriers to achieving hopes and ambitions

Respondents were asked what makes it difficult to achieve the stated hopes and ambitions for their child. The answers to this question were wide ranging, despite common hopes and ambitions between families.

Some answers identified broader national or global factors creating barriers to achieving their hopes and ambitions for their child.

For example *"The world, you just don't know what's going to happen as she gets older."*

"The system, austerity."

Factors that help to achieve hopes and ambitions

A range of factors were also identified as helping to achieve these hopes and ambitions ranging from support and services to equipment and access to expertise. Some respondents were able to identify things that were already helping, while other answers suggested families were still waiting. The support of trained staff with an understanding of the child and the availability of technology were identified as making a significant difference to whether hopes and ambitions could be achieved.

"Excellent teachers and a small community"

"The college he is at right now. Funding to continue there."

"A supportive school that don't give up on her and support despite her challenging behaviour."

"use of a tablet at school would really help"

"Having patient, trusted adults with him, who have the time and means to understand him and gain his confidence."

"Support from those professionals who have a good understanding of the needs and difficulties faced by our child"

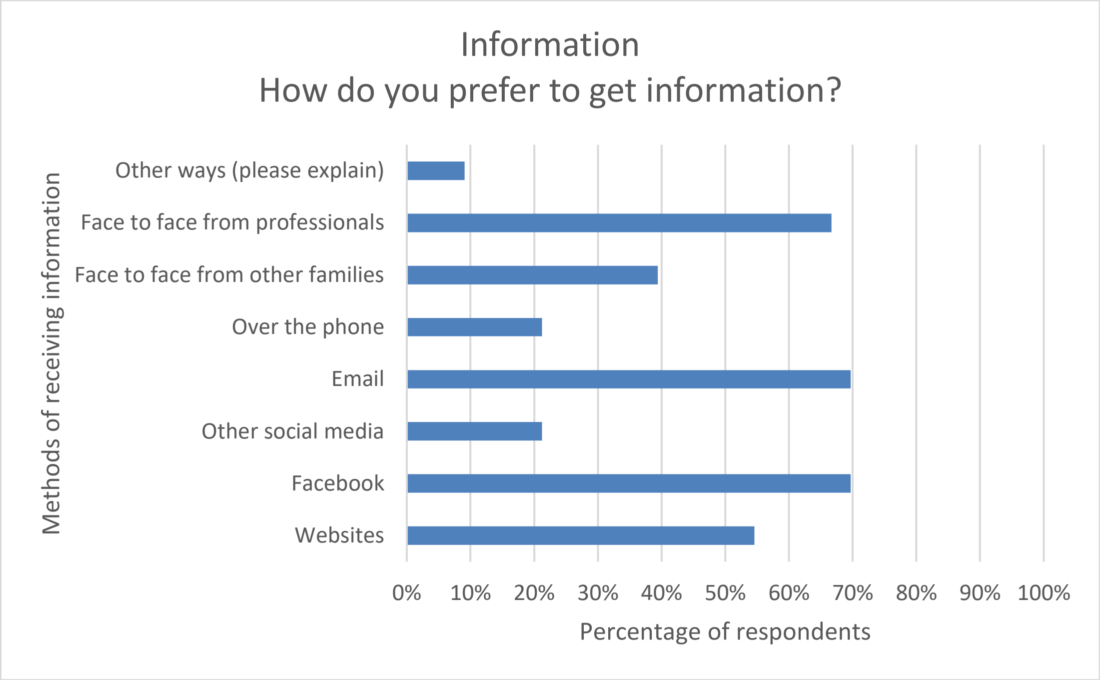
"No idea as some days it takes hours for him to be able to get out of bed, get washed and dressed. We are working on it with autism practitioner but it's very long process"

"At the moment nothing."

Information- what is needed/ available?

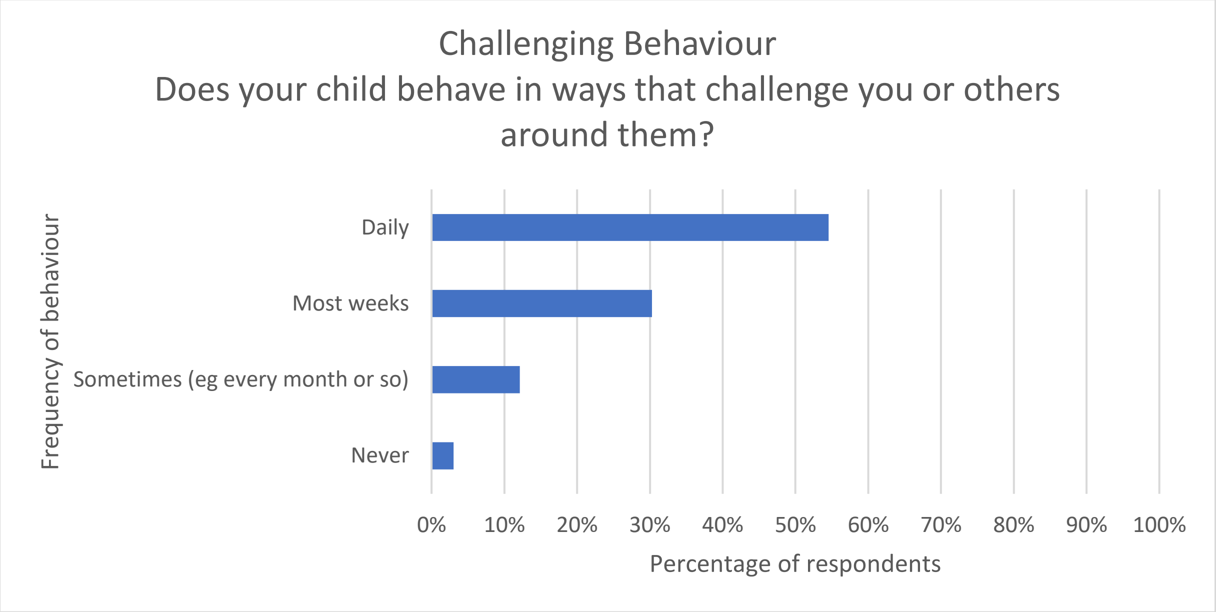
Information about supporting a child who displays challenging behaviour, and information about local support and services were most needed by survey respondents (75%). Almost as many respondents (69%) also said they would find information about supporting a child with autism helpful.

As is shown in the graph, Facebook, email, and face to face contact with professionals were the preferred ways to receive relevant information.



Behaviour (including support available)

Over half (55%) of families said their child behaved in ways that challenged them or others around them on a daily basis. Even with the relatively low response rate to the survey this suggests at least 20 families are coping with challenging behaviour from their child every day. A further 30% said their child behaved in ways that challenged most weeks.



Impact of behaviour on access to services

We asked respondents about the impact of their child's behaviour on ability to access services that are currently available. Survey respondents answered along a scale from very negative impact to very positive impact. All those who responded said the behaviour either had no impact or impacted negatively. 39% of respondents said the impact on ability to access services was very negative, 24% said the impact was negative, and 36% said there was no impact. Therefore, none felt that having a child exhibiting challenging behaviour increased their chances of accessing support.

Of those who had asked for help with their child's behaviour, at least 50% approached a combination of school, GP, community learning disability team, and the paediatrician. Almost three quarters (73%) of those who asked for support received it, however, 50% of respondents were unhappy with this support.

Half (50%) of those who approached paediatrics found that the service was not able to see their child.

Methods currently used for managing behaviour

Respondents used a variety of methods to help manage their child's behaviour. Some used PBS, including trying to understand what their child's behaviour is communicating and responding to their needs.

“try to use a PBS approach, noting her non verbal sign of distress. Creating an environment where she has choice and the world is predictable by using visual planners. I try to understand what the behaviour is communicating and respond to her needs. I don't always feel I do it well but I do try.”

“Watching out for indicators to help avoid or minimise the behaviour. Identify toys/spaces/strategies that help him to calm. Clear concise communication including hand signals and visual prompts. Planning ahead and having an exit strategy”

“Trying to avoid escalation. Giving information in advance of change and limiting new or different things. Providing consequences where needed and support.”

“With a variety of strategies, sensory input and medication.”

“We try to support him, use distraction and talk things through when he is calmer.”

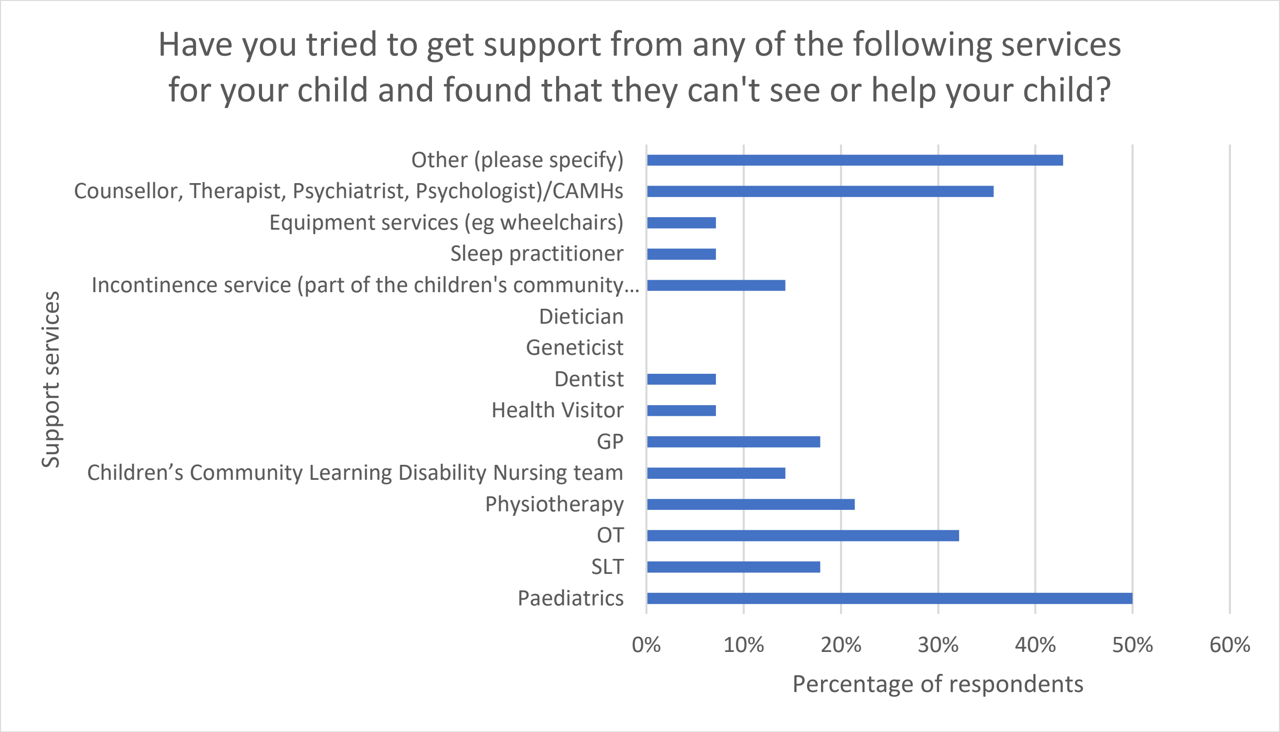
A few responses suggested that managing their child’s behaviour was difficult. For example:

“With great difficulty. Some days I don’t manage it. We all find it distressing and frustrating.”

“I don’t always feel I do it well but I do try”

Health services

The survey results suggest a large gap between both the mental and physical health services families believe their children need, and the help they reported being able to access. In addition to the 50% of respondents who failed to get support from paediatric services, 35% tried (but failed) to access support from counsellors, therapists, psychiatrists, psychologists/ CAMHs. 32% of respondents had tried to access help from occupational therapists but had not been able to.



Over 40% of respondents answered ‘other’. Within the ‘other’ category respondents expressed that they had found services were useful for providing help in some areas but not in others. One respondent, for example, said that the Occupational Therapist had been very helpful for equipment and house adaptions but not for sensory assessments. Another respondent also said the Occupational Therapist had not been helpful regarding sensory issues.

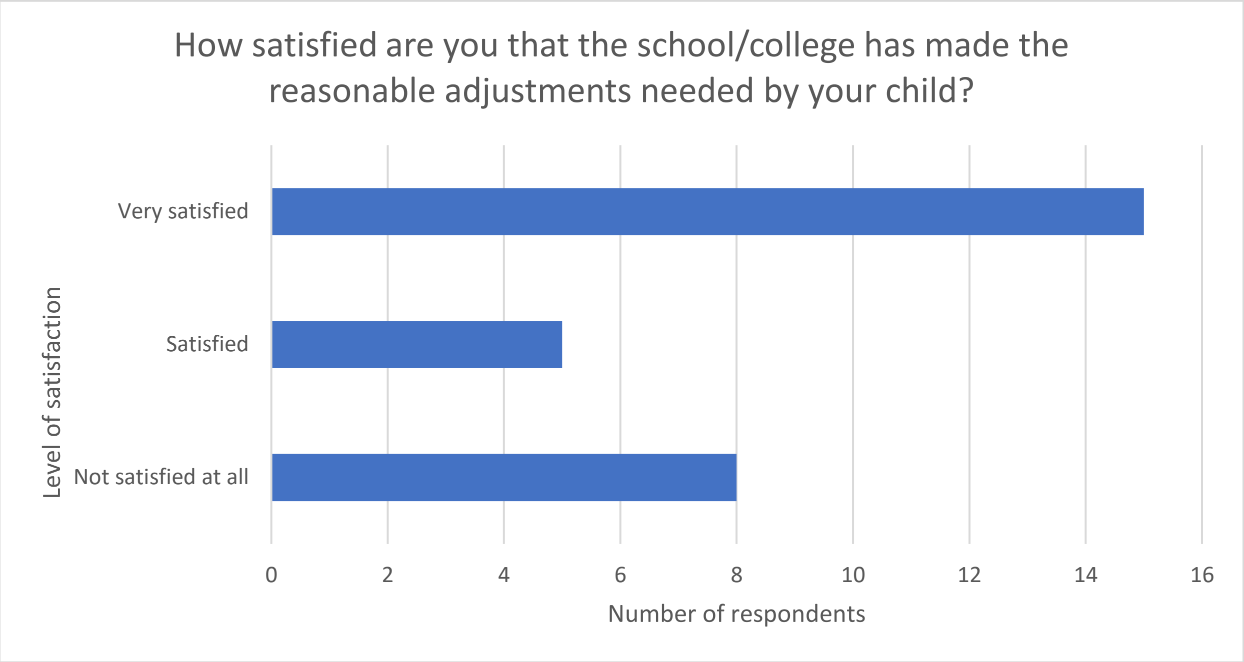
A few respondents also said CAMHs didn’t accept referrals or did not provide support because the difficulties being faced by their child had been linked to autism.

Furthermore, almost half of respondents answered no when asked if they knew how to get a referral to find the health support their child may need. These results are concerning as we know unmet health needs can be a cause of challenging behaviour and that, nationally, people with learning disabilities experience significant health inequalities.

Education (including behaviour at school)

Of those who responded to this question, 80% had a child who attended school. 80% of children had an Education, Health and Care plan.

Overall, respondents were satisfied that schools/ colleges were making reasonable adjustments. 72% of respondents were either satisfied or very satisfied with the adjustments made by schools, compared to 28% who were not satisfied.



Social care support and impact

Just over half (58%) respondents had tried to access social care support for their child. Respondents had mixed experiences in the process:

‘Had for a while but sporadic’

‘Initial assessment was quick when asked for.’

However, of those who attempted to access social care support, only 58% of the 18 had been successful in receiving social care support for their child. Even fewer found this support helpful.

SEND Reforms (awareness and impact)

More survey respondents were aware of the SEND reforms than had benefitted from them. Of the Cumbria Parent Carer Forum, The Local Offer, and the SENDIASS service, awareness of the Cumbria Parent Carer Forum was highest with 74% (23) people having heard of it. 62% of survey respondents had heard of The Local Offer and just over 50% of respondents had heard of the SENDIASS service. However, less than half of those who had heard of the Cumbria Parent Carer Forum were involved. The SENDIASS service was rated most useful out of the three. However, it is important to note that the services weren’t directly compared to each other and different people might have used different services.

Transforming Care

Survey respondents were asked about Transforming Care, their involvement and its impact. 80% of respondents had not heard about Transforming Care, and only 1 respondent had been involved in consultations on Transforming Care.

The lack of awareness of SEND reforms and the Transforming Care programme is concerning. It highlights that this survey has reached families that other projects which should be engaging with families have not reached.

Conclusions

National context

The results of this survey are relevant to national work and should be understood in the context of existing guidelines. NICE guidelines and quality standards on learning disabilities and challenging behaviour and various work being led across Government at present could have a significant impact on improving support and early intervention for children with learning disabilities or autism whose behaviours are described as challenging.

There are commitments to children with learning disabilities and autism within the NHS Long term plan, however, the number of children in Assessment and Treatment units are currently rising. There is little clarity on how the Long Term Plan commitments will be delivered in partnership with Department for Education despite the fact that much of the early intervention and prevention work will need to take place in the early years and within schools.

A report published in May 2019 by the Office for Children’s Commissioner “Far less than they deserve” calls for much better community provision for children with learning disabilities or autism whose behaviours challenge. Experts agree that this should include significant investment in early intervention.

Conclusions from this survey

We know from the national work of the Challenging Behaviour Foundation that families of children with learning disabilities or autism whose behaviours challenge are often isolated and hard to reach. Families faced with complex and difficult challenges are often not plugged in to wider networks such as Parent Carer Forums or more mainstream special needs support networks and may not have the time or energy to respond to requests for their input, if it will not have a direct impact on their child’s support.

We do not know why the response rate for this survey was relatively low, but this may have been a contributory factor. We subsequently found that another survey for families commissioned by the North East and Cumbria Transforming Care Board was open at the same time. The Transforming Care survey was shared alongside a short video by a local family carer and was discussed at a range of groups which families attend, giving it much greater visibility. Although that survey had a high response rate, most respondents lived in the North East, rather than Cumbria. It is important that findings from both the Transforming Care survey and this survey are considered together as there may be common themes and overlaps.

The Challenging Behaviour Foundation were dependent on partners to distribute the survey, so we were not in control of how and when the survey was shared, or whether reminders and prompts were circulated. It may be that better processes could be established in future.

It is also likely that more creative ways are needed to reach and involve some of the more isolated families, to ensure their experiences inform future work.

We are grateful to those families who did respond. We hope their responses will be useful to the Early Intervention Steering Group and to education, health and care services in Cumbria.

Our analysis is that the survey results suggest three main issues raised by respondents require further exploration with families in Cumbria.

- How to provide better **local information and support to families** bringing up a child with learning disabilities or autism whose behaviours challenge. At least 20 of the families responding to the survey reported challenging behaviour from their child on a daily basis. Three quarters (75%) of respondents said they wanted more information about supporting a child who displays challenging behaviour and about services that could support them.
- Further exploration of **unmet health needs (both physical and mental health)** among children with learning disabilities or autism in Cumbria. Concerningly, 50% of respondents to this survey who tried to access Paediatric care for their child were unable to do so and 35% were unable to access mental health support. Almost half were unaware of how to get a referral to health services they may need for their child.
- Exploration of how to **involve families in co-production** of the delivery of the NHS Long Term Plan commitments for children with learning disabilities and autism; potentially building on the SEND infrastructure. A majority of respondents were aware of the Local Offer, the Parent Carer Forum and SENDIASS, yet 80% were unaware of Transforming Care, with only one respondent having any involvement.

Next steps

Based on the results of the survey we propose the following next steps for the Steering Group:

- Consider the results of this survey alongside other similar issues/ similar research
- Work with families to:
  - Present the findings (and those of the focus groups) to relevant organisations and boards e.g. the Transforming Care Board and the Children with Disabilities sub-group
  - Develop easy to access information resources
- Work with the Cumbria Parent Carer Forum, the Local Offer and SENDIASS service to improve access to their services.

References

Learning disabilities and behaviour that challenges: service design and delivery, NICE guideline (March 2018)

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, NICE guideline (May 2015)

Learning disabilities: challenging behaviour, NICE Quality Standard (October 2015)

‘Far less than they deserve’ Children with learning disabilities or autism living in mental health hospitals. The Children’s Commissioner for England (May 2019)

Interim report: Review of restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability or autism. The Care Quality Commission (May 2019)

Appendix A

Cumbria Early Intervention survey questions

Where you live

1. Please type in the first half of your postcode (this will not be used to identify you)

About your child

2. Please tick any of the following statements which apply to your child. You can tick more than one - as many as apply.

   My child has

   - *been diagnosed with a learning disability*
   - *been diagnosed with a severe learning disability*
   - *been diagnosed with a profound and multiple learning disability*
   - *been diagnosed with autism*
   - *been diagnosed with aspergers syndrome*
   - *a suspected learning disability (but no diagnosis)*
   - *suspected autism (but no diagnosis)*
   - *other (please explain in your own words)*

3. How old is your child?

   (drop down options 0-25)

4. Is your child

   female

   male

5. Is your child's MAIN way to communicate (please select one)

   Verbal, using speech

   Using sign language/Makaton

   Using Picture Exchange Communication

   Using objects of reference (eg using a cup to indicate thirst or getting shoes if they want to go out)

   Using other alternative forms of communication support (please explain here)

   Not possible to define one main form of communication

6. If your child uses other forms of communication as well, please tick all that apply.

Verbal, using speech

Using sign language/Makaton

Using Picture Exchange Communication

Using objects of reference (eg using a cup to indicate thirst or getting shoes if they want to go out)

Using other alternative forms of communication support (please explain here)

7. Does your child:
   - *Live at home*
   - *Live away from home (please specify where)*
8. Can you describe briefly your hopes and ambitions for your child? (open text)

9. What, if anything, makes it more difficult to achieve those hopes and ambitions? (open text)

10. What, if anything, helps to achieve those hopes and ambitions (open text)

Information

This section asks about what information you need and how you would like to receive it.

11. What information would you find useful?

    Information about supporting a child with learning disabilities
    Information about supporting a child with autism
    Information about supporting a child who displays challenging behaviour
    Information about financial support
    Information about practical support for families of disabled children
    Information about support and services available in Cumbria
    Information about keeping in touch with other families
    Other (please specify)

12. How do you prefer to get information? (Tick as many as apply)

    Websites
    Facebook
    Other social media
    Email
    Over the phone
    Face to face from other families
    Face to face from professionals
    Other ways (please explain)

13. How easy have you found it to get the information you need?

(Scale from very difficult to very easy)

Comments…

Behaviour Support

This section asks about challenging behaviour, its impact and any support you have had.

14. Does your child behave in ways that challenge you or others around them?

    Never

    Sometimes (e.g. every month or so)

    Most weeks

    Daily

15. What impact does the behaviour have on your child?

(Scale from v negative impact e.g. they suffer significant physical or emotional harm, to no impact,)

16. What impact does the behaviour have on your family?

(Scale from v negative e.g. physical injury or mental health problems in family members, through to no impact)

17. What impact does the behaviour have on your ability to access services?

(Scale from v negative e.g. unable to attend school or access normal activities, through to no impact)

18. How old was your child when they first started to show signs of challenging behaviour?

(drop down 0-25)

19. Have you asked for help with your child's behaviour?

    Yes

    No

20. If yes, who have you approached for support?

    school

    GP

    Community learning disability team

    Carlisle Mencap

    Autism Charity

    Early Intervention team

    Paediatrician

    Health Visitor

CAMHS

other) (please say who)

21. Did you receive any support?

Yes

No

Comments

22. How happy were you with the support you received?

(Scale from v unhappy to v happy)

23. How do you manage your child's behaviour?

(open text)

Health Services and Professionals

Physical and mental health issues can be a cause of challenging behaviour. We want to know if there are needs which are not being met by health services.

24. Have you tried to get support from any of the following services for your child and found that they can't see or help your child? (Please tick all that apply)
Paediatrics
SLT
OT
Physiotherapy
Children's Community Learning Disability Nursing Team
GP
Health Visitor
Dentist
Geneticist
Dietician
Incontinence service
Sleep practitioner
Equipment services (e.g. wheelchairs)
Counsellor, Therapist, Psychiatrist, Psychologist/ CAMHs
Other (please specify)

25. Do you know how to get a referral to find the health support your child may need?

Yes
No
Comments

26. Which health needs does your child have which are not being met?
    (open text)

Education

Understanding and addressing the reasons behind challenging behaviour can be key to enabling children to learn. This section asks about how well your child's school or college does this.

27. Does your child attend a school or college?

    Yes

    No

28. Which school or college does your child attend? (This information will not be used to identify them)

(Open text)

29. Does your child have an Education, Health and Care plan?

    Yes

    No

30. How satisfied are you that the school/college has made the reasonable adjustments needed by your child?

(Scale v satisfied to not satisfied at all)

31. How well do you think the school/college is managing your child's behaviour?

(Scale v well to not well at all)

32. How well does the school listen to and work with you as a parent to address your child's behaviour?

(Scale v well to not well at all)

30.Please add any additional comments about school

Open text

Social Care

Disabled children are entitled to a Social Care assessment of their needs. This section asks about access to Social Care support.

33. Have you tried to access any support from Social Care?

    Yes

    No

    Comments…

34. Do you receive any Social Care support? (eg a Social worker, access to short breaks, direct payments)

    Yes

    No

    Comments

35. If yes, How helpful has this support been?

(Scale v helpful-not helpful at all)

36. If no, what has the impact been?

    (open text)

SEND reforms

The reforms to SEN and Disability provision brought in new arrangements which should provide extra information and support to families. This section asks whether you are aware of them or have used them

37. Have you heard of the Cumbria Parent Carer Forum?

38. If yes, Are you a member of the forum?
39. If yes, How useful do you find the forum?

(scale v useful-not useful at all)

40. Have you heard of the Local Offer?
41. If yes, have you used the Local Offer?
42. If, yes, how helpful did you find the local offer?

(scale v useful to not useful at all)

43. Have you heard of the SENDIASSS service? (It used to be the Parent Partnership)
44. If yes, have you used the SENDIASS service?
45. If yes, how useful did you find the service?

(scale v useful to not useful at all)

46. Please add any additional comments you have here about these services…..

Transforming Care support

Transforming Care is a national programme which was set up because too many people with learning disabilities or autism whose behaviours challenge are being sent out of area to assessment and treatment units. It aims to improve community support.

47. Have you heard of Transforming care?

    Yes

    No

48. Have you been involved in local consultations about Transforming care?

    Yes

    No

49. Has your child had any involvement with the programme (eg a Health, Education and Treatment review or listed on the Dynamic Risk Register)?

    Yes

    No

50. If yes, how helpful has this been?

    (scale v helpful-not helpful at all)

    Please explain in your own words what impact this has had.

Thank you for completing this survey. All responses will be anonymous. The results will be used to inform the Cumbria Early Intervention Project.