

Services for children with learning disabilities whose behaviours challenge

A survey of families' and professionals' experiences

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Many thanks also go to all of the family carers and professionals who kindly took the time to complete our surveys.

Introduction

This report presents the findings from surveys of families with children with learning disabilities whose behaviour challenges, and professionals who work with this group. The research is part of the Early Intervention Project (EIP), which aims to facilitate improved early intervention across the country to improve the quality of life and outcomes experienced by children with learning disabilities whose behaviour challenges. The project is funded by the Department of Health and jointly carried out by the Challenging Behaviour Foundation (CBF) and the Council for Disabled Children (CDC).

Web surveys of families and professionals were carried out between November 2014 and January 2015 to collect baseline evidence on awareness of, and access to, a range of support for children with learning disabilities whose behaviour challenges, and the kind of challenges families face. The surveys will be repeated next year to see if any progress has been made in relation to awareness of and access to support, and to what extent families and professionals believe any changes may be partly attributable to the work of the EIP.

The samples for the surveys were drawn from the CBF mailing list, therefore those who took part are not a representative sample of families with children with learning disabilities whose behaviour challenges and professionals who work with this group, but they are representative of the kind of families and professionals who engage with the CBF.

The survey of families

Challenging behaviour onset and referral

This survey included 61 parents/carers of children aged 0-18 and achieved an estimated response rate of 65%¹. The children's age profile and when they started showing signs of challenging behaviour are presented in Table 1. In line with the recent evidence review carried out as part of the EIP², these results show that in 70% of cases signs of challenging behaviour started in the early years. However, most families who are in contact with the CBF have older children, suggesting that it may take considerable time for families to access help.

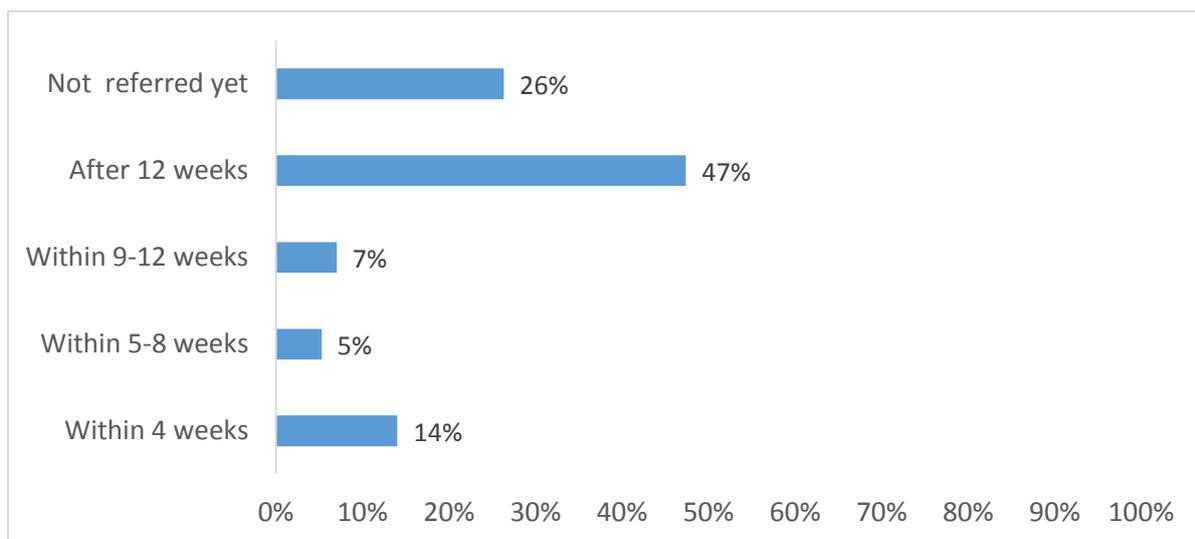
¹ The CBF Family Carers' Email Network, which was used as the sampling frame, includes 260 families, with 94 of these being eligible for the survey as they have children aged 18 or under.

² The Challenging Behaviour Foundation (2014) *Early Intervention for children with learning disabilities whose behaviours challenge – Briefing Paper* <http://www.challengingbehaviour.org.uk/cbf-articles/latest-news/eipbriefingpaper>

Table 1: Children's age profile and age challenging behaviour started

	Child's age	Age challenging behaviour started
	%	%
Under 5	5	70
5-10	32	19
11-16	54	7
17-18	9	4
N. of respondents	57	57
Missing	4	4

The survey explored what happened when children started showing signs of challenging behaviour. As Figure 1 shows, nearly half of respondents said their children were referred to a specialist after more than 12 weeks, while a quicker referral seems far less common.



Respondents=57 Missing cases=4

Figure 1: How long it took to refer child to a specialist after s/he started showing signs of challenging behaviour

Comments of parents/carers on the slow response of services

'My child was very young when she started to show signs of challenging behaviour, in her case, self-harming. She was already in a SEN nursery and when I talked to staff about it, it was described as terrible twos and I was told to deal with it. It took at least a year before, after she head-butted a teacher, we were referred to the learning disability team. Our LD nurse was then signed off sick so it took two years before we could access help. ...It would have been great if, when she first started showing signs of self-harm, we had been believed and referred immediately. Behaviours became ingrained and now we have a much greater problem than we should.'

'Referral to community mental health services [was] declined due to lack of resources. Still waiting six months on for occupational health assessment. No one to do speech therapy available.'

'Awaiting diagnosis before we can move forward and processes have taken too long.'

'Was referred to social services over a year ago by school, still have heard nothing. Behaviour is much better at school so they probably don't see a need to give us help as we cope. We have two boys with special needs and have been pretty much left to get on with it.'

'His diagnosis of his primary needs was very, very late and we have been in crisis management from the beginning.'

Usefulness of referral

Parents and carers who had been referred to a specialist service were almost evenly split between those who said the referral was useful in identifying the causes of challenging behaviour (48%) and those who did not think it was useful (53%).

Respondents were asked what kind of information they were given to understand their child's behaviour and the support available to deal with it. Most families were not provided with the kind of information and advice identified by the EIP evidence review as being effective in preventing the escalation of problems:

- Just under a third of parents were given information on the causes of their child's challenging behaviour (31%) and about local services that could support their child (30%).
- 41% were given information about Positive Behaviour Support (PBS).

While a minority of parents were provided with relevant information and advice, when this information was provided, most parents found it useful.

Lack of information and understanding of what families go through was one of the most common issues respondents mentioned when asked what additional support they would have liked.

Comments on additional support families would have liked

'Our problem was that we fell out of the loop and were never told about all these services or that we needed them as they thought our child was going to die as she was born so early.'

'Professionals listening to parents' views in the early stages would have been beneficial.'

'Being told what services are available to suit specific needs.'

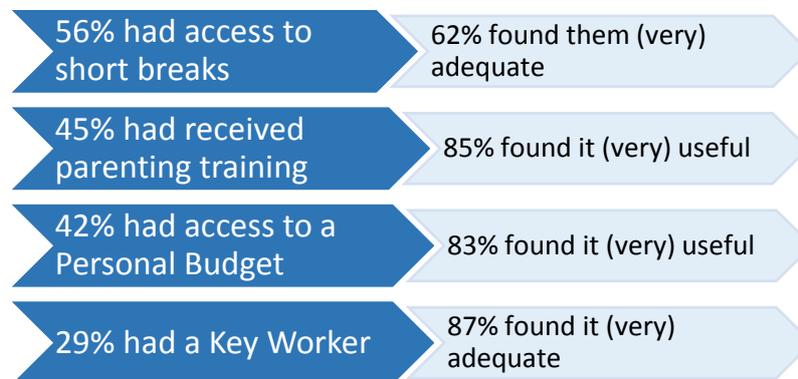
'Don't know as not told about anything else.'

'For the doctors and health care professionals to LISTEN TO THE PARENTS.'

'To be listened to as a parent from the start would have been very helpful for my child.'

Support received

Support arrangements identified by the EIP evidence review as key to effective intervention were not available to many families. Only 29% had a key worker, 42% had a personal budget, 45% had received parenting training, and 56% had access to short breaks. When families did manage to access different types of support, views were mostly positive, although there were variations:



Short breaks were reported to be 'very adequate' or 'adequate' by less than two-thirds of respondents who had access to them. Comments added by some parents/carers (and also professionals reported in the next section) indicate that the low quality of some of the provision, and the fact that it is not locally-based, were two of the reasons for dissatisfaction with short breaks. Most respondents who had received parenting training said it was useful (83%), but an issue a number of parents/carers reported was the failure to provide this training at home in the 'normal environment' where the learning is then mostly applied. Nearly three-quarters of respondents who had access to a Personal Budget said these were useful. When they did not find them useful, comments suggest that it may be because there were no adequate services locally they could buy. Although most parents who had a Key Worker thought this was adequate, some parents did comment on the lack of relevant experience of some Key Workers, and failure to promptly replace them when they moved on.

The overwhelming majority of children (86%) were in a special educational institution, while 12% were in mainstream education.

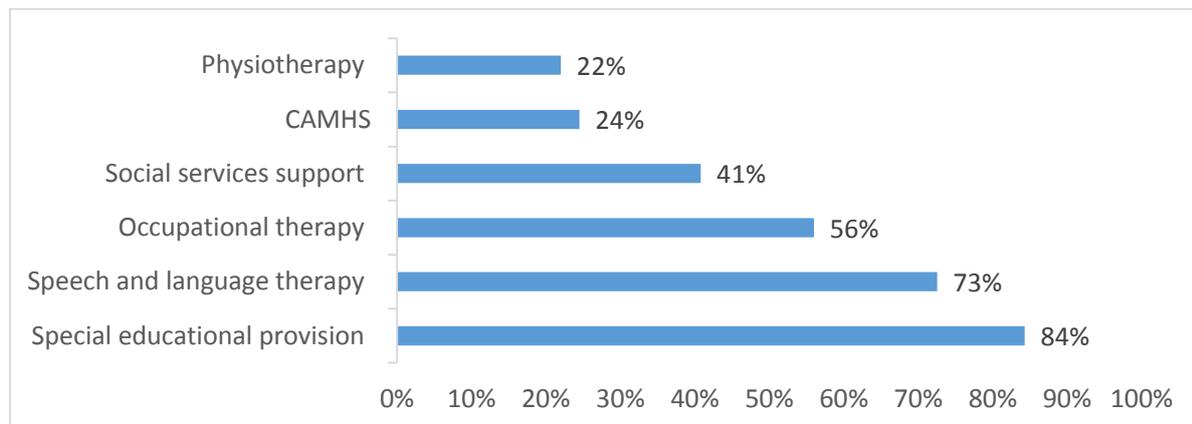
The survey found that 39% of children were not receiving specialist behaviour support. Among those who were receiving this support, in just over half of cases (51%) it was delivered in an educational institution, in 14% of cases at home, and in 12% of cases elsewhere.

Figure 2 shows that while most (but by no means all) children were receiving special educational provision (84%) and speech and language therapy (73%), other forms of support were less common. Respondents' comments suggest that low usage may reflect unmet needs, as families were unable to access relevant services:

Comments on difficulty accessing relevant services

'Any support would have been helpful ... though I have had various agencies involved over the past six years, no support has actually been put into place.'

'I would like some respite as I currently don't get any, and some help in managing my son's behaviour at home. I have been told I will get this support on numerous occasions over the past six years, only to not receive it, or to get it and having to end it as it was unsuitable.'



Respondents=51 Missing cases=10

Figure 2: Types of support children receive

The findings on how long it takes to access help highlight again the slowness of services' responses: around half of families who were accessing the support outlined in Table 2 waited more than 12 weeks for a referral.

Table 2: How long families waited for a referral

	Special educational provision	Speech & language	Occupational therapy	Social services support	CAMHS	Physiotherapy
	%	%	%	%	%	%
1-4 weeks	29	22	11	20	15	20
5-8 weeks	5	16	11	5	15	10
9-12 weeks	10	14	14	20	8	10
Over 12 weeks	57	49	64	55	62	60
N. of respondents	42	37	28	20	13	10
Missing	1	-	-	-	1	1

Predictably, special educational provision was delivered predominantly in educational institutions (Table 3), but so were speech and language therapy, occupational therapy and physiotherapy. Social services support was most likely to be delivered at home, although around a third of children also received occupational therapy and CAMHS at home. The latter was the service most likely to be delivered in a clinic.

Table 3: Where support was delivered

	Special educational provision	Speech & language	Occupational therapy	Social services support	CAMHS	Physiotherapy
	%	%	%	%	%	%
School/college	95	89	82	40	46	70
Nursery, play-group, childminder	-	3	-	-	-	-
Clinic	-	8	18	-	38	20
Home	5	8	32	60	38	10
Other	2	11	-	15	8	10
N. of respondents	42	37	28	20	13	10
Missing	1	-	-	-	1	1

NB: Respondents could choose more than one category

Parents commented on the lack of home-based support to complement the support children receive (or do not receive) in other settings. They saw home-based support as being vital to understand and deal with challenging behaviour, and prevent children from being placed in residential care.

Comments about the importance of home-based support

'I would like someone to come and teach me how to use the strategy at home with my child. I attend a lot of meetings but find it difficult to apply the information at home.'

'Hands-on intervention (modelling actual strategies in the environment they occur rather than just talking about what may help, coaching parents etc.) in the home to help parents to manage the behaviours at home for themselves.'

'Having clear pathways of support across home and school based on PBS. As this can be expensive, a lot of LAs and CCGs do not fund the appropriate support, yet it would be cost-effective to do so as otherwise children and young people easily end up in expensive out of area residential placements that are costly and take them away from their family.'

'Increased funding would...allow provision of more intensive support for families which is what is often needed, e.g. therapists to go into the home to support behaviour change, coach parents and support the implementation of behaviour management plans.'

'Regular home visits from behaviour support team, good training in behavioural methods e.g. functional assessment, enough input to be able to set up and monitor behaviour strategies, not just leave parents with a plan.'

'More home...behavioural support. There is none. More respite care put in at home. Our son would keep us up at night and having a large house we could have accommodated a carer. This was never considered. ... Sending my son to a residential school - that resembled a zoo - was not in his best interests or ours. I feel cheated and let down.'

'Challenging Behaviour team within the home and school and overnight carers within the home - all asked for and none given, and as a consequence sent to a residential school at a cost of £400,000 to the tax payer. How much would it have cost to have this at home? And what cost to our emotional state as a family in sending him 130 miles away?'

Among families who had accessed different services, views on effectiveness varied depending on the type of support (Table 4):

- Services rated as 'very effective' or 'effective' by the highest proportions were occupational therapy (82%), special educational provision (81%), and physiotherapy (70%).
- CAMHS were rated as 'very effective' or 'effective' by 61% - a number of comments from parents/carers (and also professionals in the next section) highlighted CAMHS' lack of expertise and resources to adequately support children with learning disability whose behaviour challenges.
- Speech and language therapy was considered 'very effective' or 'effective' by 55% respondents.
- Less than half of respondents (45%) rated social services support as 'very effective' or 'effective'; a number of comments later on illustrate the difficulties families faced when dealing with social services.

Table 4: Effectiveness of the support the child received

	Special educational provision	Speech & language	Occupational therapy	Social services support	CAMHS	Physiotherapy
	%	%	%	%	%	%
Very effective	36	22	25	15	23	-
Effective	45	35	57	30	38	70
Not effective	17	32	14	35	15	20
Not at all effective	2	11	4	20	23	10
N. of respondents	42	37	28	20	13	10
Missing	1	-	-	-	-	1

As we have seen, many parents were not receiving the different types of support explored by the survey. Furthermore, when we asked what would have helped their child many of these services were mentioned, including: information about managing the child's behaviour and about local services; Positive Behaviour Support; short breaks; training for parents (including managing challenging behaviour and developing care plans); a key worker, and access to CAMHS. Other types of support mentioned were:

- Independent living skills
- Sensory profile from Occupational Therapist
- Sensory processing therapy
- (Cheaper) after-school and holiday clubs/provision
- Applied Behaviour Analysis (ABA)
- Personal assistant with experience of supporting children with learning disabilities whose behaviour challenges
- Help for siblings

As well as commenting on unmet needs for specific support, parents/carers also commented on what prevented them from getting the support their child needed.

Comments on barriers to getting the right support

'We have fought personally through Tribunals for all of our son's therapies and resources - nothing was ever given based on need.'

'In another area locally a charity runs an adapted Triple P programme for parents of children with additional needs. This wasn't available to us. Health visitors and school nurses do not know how to help. We have also really struggled to access any physical intervention support to keep everyone safe.'

'Terrific ignorance in LA children's services about what challenging behaviour is, what a proper behavioural approach is. CAMHS has no-one trained to deliver PBS - they pretend they can cover the base using something very much less, i.e. meeting with workers once and after a talk or two on the phone. NOT observing or working with the child. NOT directly training parents or staff. CAMHS don't have the skills they also don't have the staff. I have had to lead on everything and fight every step of the way.'

Comments on barriers to getting the right support (cont.)

'We have received no support from social services or the early intervention team regarding behaviour. All the information etc. is what I have gained myself through training to be a parent trainer for the Challenging Behaviour Foundation.'

'Professionals need to listen to and work alongside parents; parents often already know the answers. The Challenging Behaviour Foundation was very helpful in helping my child to be re-integrated into school, this has also been successful because the Head Teacher listened and learned from us, the parents. Parents should not be underestimated because we know children best and love them more than any care worker or professional.'

'We were very well supported, but when behaviour became very challenging, a lot of that support dropped away as it was not able to cope. My son is not the only child in this position, but policies seem not to recognise him or others in his situation. Some of this is as a result of multi-agency working, which is brilliant when it works but when it falls down no one can own the problem.'

'We have had to manage all our son's needs ourselves from the outset including paying for private therapists and for diagnoses...His provision is not coordinated or joined up and we have to try and do that ourselves. That is one of the reasons his school placement fell apart this year and also because no one really understands our son and his needs and assumed he was like others. We have also struggled to get basic things like blood tests - we have one outstanding for a year. And it is hard to get carers so we cannot use most of our direct payments and the only residential four night break we have was cancelled this year because of new Ofsted rules.'

'I have reports saying he needs specialist behavioural intervention, i.e. PBS, but neither the LA (education/social care) nor the NHS will deliver it. I have been to court and Tribunal over this.'

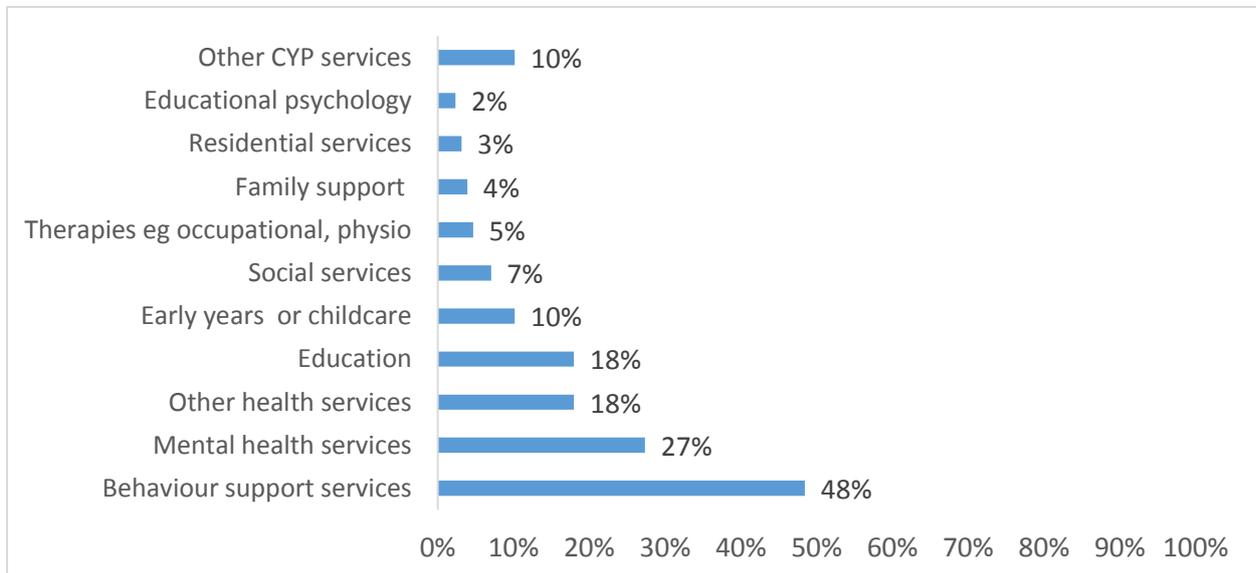
The final quote below perhaps best summarises some of the key survey findings in terms of what families need (and do not need):

'Help not judgement, respite not removal, care not manipulation, social care not social services.'

The survey of professionals

Professionals' lines of work

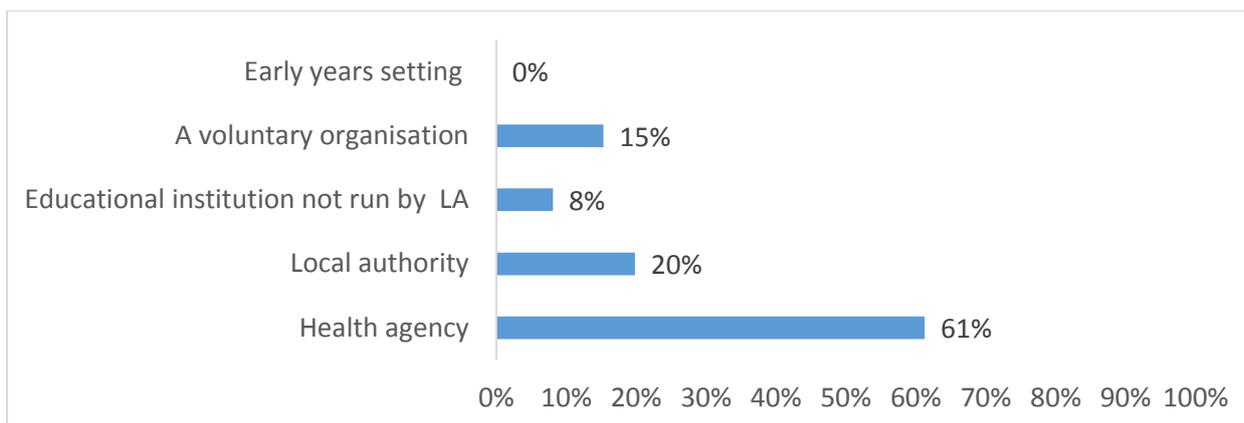
A total of 128 professionals responded to this survey³. Their areas of work and sectors are shown in Figures 3 and 4 respectively, while Table 5 shows their experience of working with children with learning disabilities whose behaviour challenges. As noted earlier, these are professionals from the CBF mailing list so they are not representative of the children's workforce as a whole: most work with children with learning disabilities, and compared with the children's workforce more generally they are likely to be more aware of the issues faced by this group of children and the type of support they need.



Respondents=128. Missing cases= 0. NB: Respondents could choose more than one category.

Figure 3: Respondents' area of work

³ It was not possible to estimate the response rate for this survey as three different mailing lists were used, and some professionals were included in more than one list. We also do not know how many of these were eligible to take part in the survey i.e. worked directly with children and young people.



Respondents=111. Missing cases= 17. NB: Respondents could choose more than one category.

Figure 4: Respondents’ sector

Table 5 N. of children with learning disabilities whose behaviour challenges respondents had worked with in past 2 years

	%
None	5
Under 10	21
11-20	22
21-30	11
31-40	6
41-50	12
More than 50	25
N. of respondents	102
Missing	26

Effectiveness and availability of support

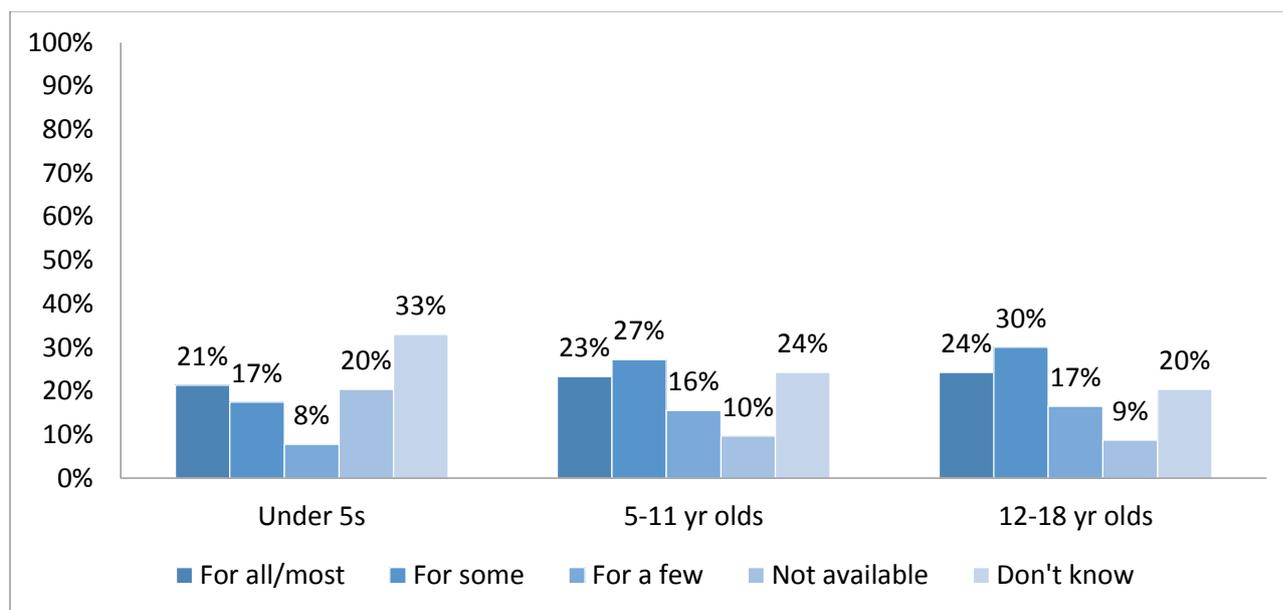
The overwhelming majority of professionals believed that regular checks and access to the support listed in Table 6 would be effective for children with learning disabilities whose behaviour challenges in most or some cases, with the exception of residential care, with 35% believing that this is rarely or never effective.

Respondents were asked about the type of support available locally. Behavioural support was reported as being available by 77%, while crisis/intensive support was mentioned by 40%, with 28% of professionals saying they did not know if it was available locally. Reasons mentioned for the lack of these two types of support included: lack of awareness, insufficient funding and lack of relevant knowledge and expertise.

Table 6: Views on effectiveness of different types of support (% to be read across)

	In most cases	In some cases	Rarely	Never	Don't know	Respondents	Missing
	%	%	%	%	%	N.	N.
Regular physical health checks	61	29	1	-	9	109	19
Regular sensory assessments	44	50	1	-	5	109	19
Training for parents	93	6	0	-	2	109	19
Residential placements	2	55	35	3	6	109	19
Short breaks	59	39	1	-	2	109	19
PBS to provide tailored care	83	12	-	-	6	109	19

Professionals were asked if, in their area, there were clear pathways across health, social care and education for children with learning disabilities whose behaviour challenges from different age groups. As indicated in Figure 4, only a minority of respondents (between 21% and 24%) said these were available to most or all children.



Respondents= 103 Missing=25

Figure 4: Local availability of clear pathways across health, social care and education for children with learning disabilities whose behaviour challenges

Professionals were asked about the training received to work with children with learning disabilities whose behaviour challenges; 76% said this training was ‘very adequate’ or ‘adequate’.

What would make a difference?

In an open question, professionals were asked what they thought would make the greatest difference to the quality of support and services provided to children with learning disabilities whose behaviour challenges. Their responses are summarised in Table 7.

Table 7: Professionals' views on what would made the greatest difference

Information provided early to families and practitioners on the causes and risks of behaviour that challenges
Better co-ordinated inter-agency work (including joint commissioning) and agencies adopting a consistent approach
Dedicated specialist, multi-disciplinary teams with relevant training and expertise e.g. PBS, ABA
Better understanding, across agencies, of causes of challenging behaviour, and a focus on early intervention and evidence based approaches e.g. ABA, PBS
Family centred care planning based on accurate assessments of need, clear goals and pathways, and guidance for parents
Working closely with families including providing training and in-home support
Better awareness, training and support for specialist and non-specialist staff
Better planning around transition to adult services
Better awareness among commissioners and managers of the needs of this group
Improve access CAMHS and their capacity to adequately respond to the needs of this group
Key worker
Locally based intensive/ crisis support available at short notice
Good quality community based short breaks
Advocacy provided to children and their parents/carers

Conclusion

The EIP evidence review identified early assessment of needs, and a rapid response to meet these needs with evidence-based programmes, as key to the kind of support that has the greatest benefits for children and their families, and can prevent problems from escalating. The survey of families from the CBF network shows that support including these key ingredients is not available to many of these parents. Their experiences were more likely to be characterised by late referrals when problems first appeared, difficulties in accessing the kind of information, advice and services families need, and agencies that are not equipped to adequately support children with learning disabilities whose behaviour challenges.

The survey of professionals shows that they are aware of the kind of support children with learning disabilities whose behaviour challenges need, as it is to be expected from a group that is linked to the CBF. However, they also pointed to big support gaps locally as they believed that most children do not have clear pathways across different agencies to provide consistent support.