

The Paving the Way project: Early intervention for children with learning disabilities whose behaviour challenges

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Summary

The project and the evaluation

The report presents the findings of the evaluation of the Paving the Way project, which was funded by the Department of Health (DH) in 2013-16. The project overarching aim was to facilitate access to early intervention to improve the quality of life and outcomes experienced by children with learning disabilities who display behaviours that challenge. The project was carried out by the Challenging Behaviour Foundation (CBF) and the Council for Disabled Children (CDC).

An independent evaluation of the project was commissioned to answer the following questions:

- Did the project achieve its intended aims and objectives?
- What were the quality and effectiveness of the project deliverables?
- Has the project made a difference?

The evaluation gathered evidence from a range of sources including project staff, project documents, surveys and qualitative interviews with key stakeholders involved in the project in different ways.

Expected outcomes from the project

From the start the project team demonstrated considerable clarity about the expected outcomes from their work. The ultimate project beneficiaries were children and young people with learning disabilities whose behaviour challenges and their carers, with expected long term outcomes being:

- Improved access to local support using a Positive Behaviour Support (PBS) approach
- Ensuring better co-ordinated multi-agency responses
- More active family involvement in the co-production of local services.

A number of intermediate outcomes were identified as necessary to achieve these long term goals, including:

1. Ensuring that relevant learning disability policies adequately cover children and young people
2. Ensuring that relevant children's policies include accurate information on effective support for children with learning disabilities whose behaviour challenges
3. Increasing awareness among professionals and commissioners of the needs of children with learning disabilities whose behaviour challenges and their carers
4. Developing examples of good practice that could be replicated locally to show what effective support looks like
5. Enabling family carers to ask for more effective support.

How the project was implemented

The project team identified three key principles underpinning their work, the expectation was that the project would be: family centred, evidence informed and grounded in partnership working. The evaluation found that the project very much 'did what it preached' and was consistent in applying these principles to its work, as well as promoting these as principles that should underpin effective service commissioning and delivery. These were also seen as principles underpinning the work of the CBF, and it was evident that in respondents' mind the project and the CBF were one and the same, the distinction between the two was somewhat artificially imposed by the requirements of the evaluation brief which was to assess the work of the project, rather than the CBF as a whole.

From the start the project team demonstrated a clear vision of who needed to be influenced (i.e. drivers of change, policy makers and those commissioning and delivering services) and through which mechanisms in order to achieve the expected outcomes outlined above.

Initially efforts focused on gathering the evidence on what effective support should look like from a range of sources, including: research literature, expert opinions, families' and services' experiences. The evaluation findings show that the project was seen as having redefined the concept of evidence base,

combining and giving equal weight to families' views and experiences, as well as research evidence and expert opinions.

Having built the evidence base, the project team developed a range of resources and tools targeted at different audiences, which were disseminated to policy makers and drivers of change through regular contacts the project team had with key national players. The Paving the Way website, which includes all the project resources and tools, as well as links to other relevant websites, was seen as providing a very valuable and much needed one-to-stop shop for families, service commissioners and professionals. National and local events were used to disseminate the project learning to service commissioners and professionals. The evaluation findings suggest a 'trickle effect' with project resources used in local events run by other organisations, while the scale of this effect appears to be small at this stage, it has the potential to grow.

The evaluation found that the project resources were considered to be very accessible and of consistent high quality, and its dissemination strategy was seen as effective. There is also evidence that the project provided good value for money, through the commitment and hard work of its staff, its success in securing pro-bono support, partnership arrangements and additional funding to maximise the potential reach and impacts of the project outputs.

Has the project made a difference?

Looking the five intermediate outcomes outlined above:

1. The project was seen as successful in ensuring that learning disability policies adequately cover children and young people. For example, the project was reported to have influenced: DH children's continuing care funding decisions; DH guide on reducing restrictive interventions; NICE guidelines on challenging behaviour and learning disabilities; and, key bodies such as the Learning Disabilities Professional Senate and the Children's Health and Wellbeing Partnership board. But above all, the project was seen as having had considerable influence on the Transforming Care agenda, as one respondent put it:
'The Transforming Care agenda opened the door to children and young people thanks to the efforts of the project.'
2. While highly regarded by officials responsible for relevant children's policies, the project seems to have been less influential in this policy arena. For example, it was reported to have had a limited influence on the SEND code of practice.
3. The evaluation found that the project filled a considerable gap by providing new learning on the needs of children with learning disabilities whose behaviour challenges (including providing the first robust estimate of the size of the group) and effective mechanisms for disseminating this learning.
4. The project was seen as having played a key role in gathering and disseminating evidence of good practice, and in demonstrating that it is possible to overcome barriers and improve services. The evaluation found examples of how the project learning and resources were used locally to improve awareness, as well as local service planning and delivery.
5. The project was seen as having created the right tools to enable carers to ask for more effective support. It was also universally seen as a strong and effective advocate for children with learning disabilities whose behaviour challenges, and having given a voice to these children and their carers.

In summary the evaluation found that the project created the learning, tools and resources necessary to improve local service planning, commissioning and delivery, with some examples of how they were being used locally. It was too early to try and quantify the level of use of the project resources locally and its impacts on local support and services, establishing these would require a larger scale evaluation later on once the project tools and resources become more widely known and used.

What does it all mean for children and families?

There was no expectation that the ultimate aim of ensuring more effective, better quality and evidence informed services reflecting the needs and wishes of children and their families would be achieved within the project three-year timeframe. Nevertheless, the evaluation identified more immediate benefits from the project for children and families:

- First, by placing children and their carers at the centre of its work, the project has enabled them to be agents of change rather than passive recipients of changes planned by someone else.
- Second, it was widely believed that the quality, range and accessibility of resources available to parents are now much better than before the project existed.
- Third, the project team has secured funding from the Transforming Care programme to deliver training to carers.

What next?

There was concern among interviewees about what will happen now that the project funding is coming to an end, as it was believed that there is a need to keep up the momentum and the project resources need to become more widely known.

Evidence from the evaluation suggests that there is the determination and capacity to build on the what has been achieved by the Paving the Way project in the past three years. The CBF saw the project as being an integral part of their work. The project has enabled them to build an authoritative evidence base, develop some high quality and effective tools and resources, and provide a one-stop shop for families and professionals. The CBF wants to maximise the reach and impacts of the project outputs by fully integrating what the project has achieved into its organisational structure, for example, the project manager will continue to work for the CBF in a new role as their children policy lead, and additional funding to promote the Paving the Way model was secured even before the project ended.

1. Introduction

The report presents the findings of the evaluation of the Paving the Way project (previously known as the Early Intervention Project), which was funded by the Department of Health (DH) through the Innovation, Excellence and Strategic Development Fund in 2013-16. The project aimed to facilitate better access to early intervention to improve the quality of life and outcomes experienced by the 41,500 children in England with learning disabilities who display behaviours that challenge. The project was carried out by the Challenging Behaviour Foundation (CBF) and the Council for Disabled Children (CDC).

An independent evaluation of the project was commissioned in November 2013, shortly after the project started, to answer four key questions:

Has the project achieved its aims and objectives?	What was the quality and effectiveness of the project deliverables?	Has the project made a difference?	Has the project provided good value for money?
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The first step for the evaluation was to develop a logic model (see appendix 1), which sets out the project short and longer term outcomes, the planned project activities and outputs, and the resources required to achieve the intended outputs and outcomes. The logic model was used to monitor the project's progress and inform the evaluation activities, with interim evaluation findings provided at the end of the first and second year¹.

Section 2 explains how the evidence for the evaluation was gathered. Section 3 outlines the project's theory of change, i.e. what were the project expected outcomes and the plan for achieving these. Section 4 sets out the key principles that underpinned the work of the project, while section 5 explores how the project was implemented. In section 6 we consider if and how the project has made a difference, and in section 7 whether it has provided good value for money. We conclude by considering what the project has meant for children and families (section 8), and what should be done next to build on the work of the past three years (section 9).

2. The evidence for the evaluation

Data to evaluate the project has been drawn from a range of sources, including:

- Ongoing review of relevant project documents, such as project plans, updates to the project steering group, a record of influencing activities kept by the project team.
- Regular meetings with the project team to discuss the project activities and progress.
- Surveys involving a total of 164 respondents to explore views on key project outputs, that is: the Paving the Way guide for commissioners; an information pack for families on Positive Behavioural Support (PBS); a national conference in March 2017 to raise awareness about the project's outputs and resources.
- Telephone interviews each year with respondents involved with the project in different ways. In total 41 interviews were carried out (12 in year 1; 10 in year 2; 19 in year 3) with: family carers; representatives of government departments and agencies; local commissioners; professionals; and, academic experts. The interviews collected qualitative evidence on: the appropriateness and relevance of the project's aims and objectives; the quality of the project's activities and outputs; and, views on the perceived impacts of the project.
- The costs of some key project outputs were compared with approximate costs for similar outputs obtained from other charities to give an indication of whether the project has provided good value for money.

¹ Evaluations findings from the first and second year can be found here: <http://pavingtheway.works/project/wp-content/uploads/2015/07/eip-evaluation-report-year-2.pdf>

More information about the evaluation methodology can be found in appendix 2.

3. The project's theory of change

From the start the project team demonstrated considerable clarity about the expected short and longer term outcomes and how these could be achieved, in other words the project had a clear theory of change illustrated in the logic model in appendix 1.

The ultimate project beneficiaries were children and young people with learning disabilities whose behaviour challenges and their carers, with the key expected **long term outcomes** being:

- Improved access to local behaviour support using a Positive Behaviour Support (PBS) approach
- Ensuring better co-ordinated multi-agency responses
- Families more actively involved in co-producing services and local offers.

A number of intermediate outcomes were identified as necessary to achieve these long term goals. **Short term outcomes** focused on ensuring that:

- Learning disability policies adequately covered children and young people
- Relevant children's policies included accurate information on effective support for children with learning disabilities whose behaviour challenges.

Medium term outcomes aimed to:

- Increase awareness among professionals and commissioners about the needs of children with learning disabilities whose behaviour challenges and their carers
- Develop examples of good practice that could be replicated to show what effective practice looks like
- Enable family carers to ask for more effective support.

From the start the project team demonstrated a clear vision of who needed to be influenced and through which mechanisms in order to achieve the expected outcomes. The following stakeholder groups were identified (see Figure 1):

- **Drivers of change** who can influence national policy and local practice, including the Learning Disability Professional Senate, the Office for Children's Commissioner (OCC), academic experts and relevant voluntary sector organisations.
- **Decision makers** who can directly or indirectly influence service provision, including: NHS England (NHSE) and particularly its Transforming Care board; the DH and the Department for Education (DfE); representatives of local services such as the Local Government Association (LGA) and the Association for Directors of Children's Service (ADCS); and, bodies responsible for setting and maintaining standards in health, social care and education, i.e. NICE, the Care Quality Commission (CQC) and Ofsted.
- Those responsible for **commissioning and delivering services** locally.

A range of outputs and activities tailored to and targeted at different groups were planned and delivered, and the evaluation focused on collecting feedback on the quality, reach, impacts and value for money of outputs targeted at different audiences. Before discussing these findings, we consider the evaluation findings on key assumptions underpinning the work of the project.

Figure 1 Paving the Way stakeholder groups



4. Assumptions underpinning the work of the project

As shown in the project logic model in appendix 1 and in Figure 2, the project’s approach was family centred, evidence informed and grounded in partnership working. These were seen by the project team as principles underpinning the work of the project, as well as principles to promote to support effective service commissioning and delivery. The evaluation found that the project very much ‘did what it preached’ and was consistent in applying these principles to its work. These were also seen as principles underpinning the work of the CBF, and it was evident that in respondents’ mind the project and the CBF were one and the same, the distinction between the two was somewhat artificially imposed by the requirements of the evaluation brief which was to assess the work of the project, rather than the CBF as a whole.

Figure 2 Assumptions underpinning the Paving the Way project



4.1 Family centred

At the heart of the project's work are children, young people and their carers. This family centred approach was evident from the initial project plan: the project kicked off with consultations to develop a vision of what effective support looks like based on children's² and carers' views³ (as well as the views of experts and professionals). The project website includes a whole section on 'Learning from families' and families' experiences and views are predominant in other sections of the site. There is also plenty of evidence showing that the families' views informed key activities throughout the course of the project, as shown in Box 1. Feedback from carers who took part in project activities suggest that their experiences were positive, and they felt their views and comments were reflected in the outputs from these activities (more information on the project activities mentioned in Box 1 is provided in section 5).

- The Paving the Way guide included children's and carers' experiences, and their vision of what effective support should look like. Carers were also involved in commenting on drafts.
- The information pack for carers on Positive Behaviour Support (PBS) started with two workshops with carers, and carers were also involved in commenting on drafts.
- The views of carers and their experiences were gathered through a survey of family carers which is now part of the evidence base provided on the project website.
- Family carers gave presentations at the national conference organised to showcase the project's work and resources, while children's voices were heard via videos produced by the project.
- Family carers were involved in a number of Transforming Care events run or supported by the project.
- Family carers were included in the evaluation and provided feedback via the surveys and the evaluation interviews.

Box 1 How families shaped the work of the Paving the Way project

The project's family centred approach was noted by virtually all respondents who took part in the interviews, who believed the project played a key role in promoting a family centred approach to service planning and delivery. As one respondent explained:

'A family centred approach is a key feature of the project, what it is known for and part of its DNA.'

A possible area of improvement identified by the evaluation was the need to involve a wider range of parents, for example, from wider geographical areas, as it was believed that carers involved with the project activities were predominantly from the South East.

4.2 An evidence informed approach

The other key defining feature of the project is its evidence informed approach, which again was evident from the start. In the initial 12 months or so efforts were largely focused on gathering relevant evidence from a range of sources, from national statistics and the academic literature to the experiences of families and services. This evidence informed approach was recognised by interviewees as a defining feature reflecting again a model of how the project operated and how services should operate. The project was also seen as having redefined the concept of evidence base, combining and giving equal weight to families' views and experiences, as well as research evidence and expert opinions.

An evidence informed approach seems also reflected in the commitment to evaluate the project and use the evaluation findings to inform the implementation of the project.

² <http://pavingtheway.works/project/wp-content/uploads/2015/12/eipfocusgroupreport.pdf>

³ <http://pavingtheway.works/project/wp-content/uploads/2015/11/a-vision-for-our-children.pdf>

4.3 Partnership working

The importance of partnership working has grown during the course of the project, while it was always important, at the start it did not seem to be considered a key defining feature on a par with the family centred and evidence informed approach. However, gradually partnership working emerged as a key strength of the project, as stated on its website, the project is seen as: 'A partnership between family carers, children and young people, commissioners, professionals and academic experts'. The evaluation findings show that this is very much its *modus operandi*, and not simply an aspiration. For example, interviewees commented on the project's ability to understand different perspectives, while guided by families' views, experiences and needs, the project team has been realistic about the barriers faced by services and aware of the need to reach a consensus through a collaborative approach. The project team has also demonstrated an ability to bring together and unify diverse stakeholder groups to communicate key messages. A particularly effective example of this mentioned by interviewees was the success in co-ordinating the input of a group of leading academics who agreed on some key messages emerging from the evidence base, and which resulted in the publication of the Evidence Policy Briefing (discussed below). It was also noted that the project has organised a number of workshops bringing together health, education and social care professionals, as well as carers, thus clearly demonstrating how partnership can work in practice. Finally, it was reported that project staff have been very good at spotting opportunities for collaborative working and when joining forces can improve their effectiveness and ability to make a difference.

Box 2 provides examples of partnership working, more details about the project activities and outputs mentioned can be found in section 5. The evaluation interviews included respondents involved in some of these collaborative activities and generally the feedback on these experiences was positive. The project was seen as a *'good partner'*, with the project manager reported to be helpful, responsive, *'delightful to work with'* and with open and honest relationships established. It was, however, noted that project staff were very stretched and this could slow down their responses and/or result in a more limited input than originally hoped or envisaged.

The project is the result of a partnership between **CBF and CDC**, which was reported to be effective as the two organisations complement each other by combining *'the passion, understanding and families' perspective of CBF with CDC acceptability within education'*, as well as extensive links with key stakeholder groups.

The work of the project was informed by a **reference group** consisting of 154 professionals and 34 family carers. The group received regular updates from the project and group members had the opportunity to shape the project's work by responding to surveys, invitations to meetings and workshops, and by providing examples of good practice for project resources and the website.

12 academics and researchers contributed to the Evidence Policy Briefing on a pro bono basis.

The project supported **Mencap** with the Transforming Care pilots which aimed to reduce challenging behaviour by equipping parents with the right skills.

In partnership with the **National Development Team for Inclusion (NDTi)** the project developed a resource which aims to improve local support for children and adults with learning disabilities and/or autism whose behaviours challenge. The project resources and its family contacts also supported NDTi to deliver regional workshops on early intervention for children and young people.

In collaboration with the **Learning Disability Professional Senate** the project has produced an information leaflet for professionals on 'When children's behaviour challenges'.

The Positive Behaviour Support (PBS) information pack for families was produced in collaboration with the **PBS Academy**, which also collaborated with the delivery of the national conference.

The project was part of a **consortium including four universities** that has submitted a bid for a trial in England to evaluate Stepping Stones Triple P, a programme for parents with children with learning disabilities whose behaviour challenges.

Box 2 Examples of partnership working

5. Project implementation

The evaluation findings show that the project was implemented as envisaged in its logic model (appendix 1):

- In years 1 and 2 efforts were focused on building an evidence base from a range of data sources. In section 5.1 we consider the evaluation findings on this work.
- The evidence base was then used to develop a range of tools and resources tailored to the different stakeholders outlined in Figure 1. In section 5.2 we present the evaluation findings on the appropriateness, usefulness and quality of the project outputs.
- While dissemination and influencing activities started from day one, the bulk of the dissemination work took place in the third year once a range of resources and tools had been developed. In section 5.3 we explore how effectively the work of the project was disseminated.

5.1 Gathering the evidence

The initial focus of the project was on gathering evidence on:

- The needs of children with learning disabilities whose behaviour challenges and their carers
- Their experiences of services highlighting gaps in provision and the effects of inadequate support
- The size of the group

- What good practice looks like and how it can be achieved
- The costs and benefits of providing more effective support.

As indicated in Figure 3, this evidence was gathered from a range of sources, reflecting the approach underpinning the project’s work: while putting evidence from families at the centre, there was also an awareness and sensitivity to other perspectives and the recognition that solutions to difficult problems require a consensus. There was also a recognition that to influence policy and practice robust evidence was needed to prove the effectiveness of alternative approaches promoted by the project (e.g. PBS).

The evaluation found that data gathering did not consist of a one-off exercise, it was an iterative process with regular opportunities for different stakeholders to comment on the emerging evidence base, and the conclusions and recommendations drawn from this evidence. For example, while a series of workshops were run at the start of the project to gather evidence on what good services look like, there were other opportunities later on for carers, professionals and experts to comment on how this evidence was used to develop resources targeted at different groups.

Figure 3 Data sources informing the Paving the Way project evidence base



5.2 Developing tools and resources

Having gathered the evidence base the project team then focused on maximising its effectiveness and potential impacts by developing a range of tools and resources targeted at different audiences, with both the content and the presentation tailored to the range of audiences outlined in Figure 1.

Evidence Policy Briefing and other evidence

One of the first project outputs was an **Evidence Policy Briefing**⁴ which included a review of research on the effectiveness of early intervention for children with learning disabilities whose behaviour challenges, and provided new statistical evidence on the size of the group. The Briefing, which was published in November 2014, was put together with the help of a group of leading academic experts. Feedback from the evaluation interviews was very positive. The Briefing was seen as a powerful document filling an important gap by providing in one place key evidence about the importance of early intervention and new evidence on prevalence. It was seen as authoritative as it was authored by key experts in the field and created a

⁴ <http://pavingtheway.works/project/wp-content/uploads/2015/07/briefing-paper.pdf>

consensus among key experts on a set of recommendations, something that may have not been possible without the project's neutral stance, and the determination and skills of the project manager.

The Briefing was extensively disseminated, with links to it on key websites⁵. The evaluation found that evidence from the Briefing was used locally to make the case for early intervention with the 'astronomical' amount spent on residential education being particularly helpful in making the case for alternative approaches, and with data on prevalence being useful for planning purposes. The project team also made extensive use of the document to brief government officials, and the evaluation interviews found that respondents from government departments and agencies were aware of this resource and the statistical evidence in particular. Accessible and user friendly presentations of this evidence for families and professionals are also available on the project website.

In the project's second year **surveys of families and professionals**⁶ were carried out to collect some statistical evidence on the kind of challenges families face, and on awareness of and access to support for children with learning disabilities whose behaviour challenges. The evaluation found little evidence that these surveys results are well known and utilised.

The project website also provides links to a **range of sources of evidence** produced by other organisations, for example: reports highlighting the inadequacy of local services and relevant policy documents.

Paving the Way guide and other resources for commissioners, providers and professionals

In April 2015 **Paving the Way**⁷ was published. This is a guide for commissioners and providers on developing effective local services for children with learning disabilities whose behaviour challenges. The guide combined evidence from the Briefing and the vision of a good service developed with families and other stakeholders, with a number of case studies gathered by the project team. The case studies illustrate different approaches to the delivery of effective support and services, with more detailed information about these provided on the project website. While developed primarily for those commissioning and delivering services, the evaluation found that the guide was seen as relevant and useful by other stakeholder groups, including policy makers, drivers of change and family carers.

An on line survey was carried out to gather views on this document. The survey found that 59% of respondents thought the guide provided new learning on the barriers faced in accessing adequate support and 77% on what effective support looks like. As shown in Table 1, different elements of the Paving the Way guide were considered useful by virtually all survey respondents, with families' stories and quotes, and service case studies reported as 'very useful' by the largest groups of respondents.

⁵ These were reported in the interim evaluation report <http://pavingtheway.works/project/wp-content/uploads/2015/07/eip-evaluation-report-year-2.pdf>

⁶ <http://pavingtheway.works/project/wp-content/uploads/2015/07/eip-survey-report-year-2.pdf>

⁷ <http://pavingtheway.works/project/wp-content/uploads/2015/08/paving-the-way.pdf>

Table 1 How useful were different elements of the Paving the Way guide

	Very useful	Useful	Not very useful	Not at all useful
	%	%	%	%
Stories and quotes from families	74	26	0	0
Case studies of services	63	35	2	0
Facts and figures	58	42	0	0
Sources of further information	55	39	5	0
The illustration of the path to better outcomes	54	46	0	0
Tips and challenges	48	50	2	0
Supporting statements from experts	47	51	2	0

Source: Survey about views on the Paving the Way guide (N=114)

Positive views on the Paving the Way guide and its potential for making a difference were also reflected in the comments survey respondents provided:

'An excellent publication with practical steps and stories that inform on the best way to support this group of young people. Easy to read and well presented. A great resource to inform and support change.'

'Paving The Way is a great resource and I wish it had been available to me when my son was diagnosed in 2003, at the age of 3, with severe autism and a speech and language impairment.'

'Paving the Way is invaluable in raising the profile of children and young people with learning disabilities who challenge and the importance of personalised approaches to providing early intervention to address challenging behaviours, and in particular to ensure that parents and mainstream children's services feel confident to deal with them.'

Views on the resources available show that family stories and videos produced by children and young people were seen as very effective in conveying key messages about families' needs, and some interviewees said they had or were planning to show the videos and share the family stories at local workshops and staff training sessions. As we have seen the family stories, which were also included in the Paving the Way guide, were reported to be (very) useful by all people who responded to the survey (see Table 1). The videos were shown at the project conference (discussed in the next section), over 90% of delegates who completed the event survey said they found them (very) useful.

In collaboration with the Learning Disability Professional Senate the project produced an **information leaflet** for professionals on 'When children's behaviour challenges'⁸. It was difficult to establish in the interviews to what extent respondents were aware of and used this leaflet, as they tended to talk more generally about the resources (for professionals) available from the project website. However, members of the Professional Senate who took part in the interviews were positive about the leaflet, both because it was seen as useful resource for professionals and because it reflected the Senate's shift to a more child centred focus.

When **Education, Health and Care (EHC) plans** were introduced, the project published an information sheet⁹ for developing plans for children with learning disabilities whose behaviour challenges. Again it was not clear from the interviews the extent of awareness and use of this information sheet, but a DH official reported that their guidance on EHC plans has a link to the project information sheet.

In partnership with the National Development Team for Inclusion (NDTI) the project secured funding from the Transforming Care programme to develop a resource outlining **local pathways** for children and adults with learning disabilities and/or autism whose behaviours challenge. The resource was developed for SEND Joint Commissioning Boards, senior managers, service commissioners and for Transforming Care Partnerships, who are responsible for improving local support for children and adults with learning

⁸ <http://pavingtheway.works/project/wp-content/uploads/2016/03/CBF-DL-Leaflet.pdf>

⁹ <http://pavingtheway.works/project/wp-content/uploads/2015/12/developingehcplans.pdf>

disabilities and/or autism whose behaviours challenge, in order to improve children's outcomes and avoid in-patient admissions and out of area placements. This resource had not been published when the evaluation report was written, so it was not possible to collect feedback on it. However, the resource provided the opportunity to disseminate important messages (e.g. about the need for family centred, multi-agency pathways which are life long and genuinely informed by families) to a key audience, and showed the project's capacity to secure additional funding to build on the work done.

In addition to the resources developed by the project team, the project website has links to resources produced by others, for example, information from the PBS Academy on how to commission services within a PBS framework, and relevant resources available from the CBF and CDC websites.

A PBS information pack and other resources for families

The **PBS information pack**, produced in collaboration with the PBS Academy, was published in spring 2016¹⁰. The pack includes resources for family carers on PBS with information on: what PBS is and what it looks like in practice; what questions to ask to check that PBS is being delivered properly; and, where carers can find information and advice on training.

An on line survey of 26 carers from the project reference group collected views on the information pack. Only 16 respondents answered the questions so these findings are very tentative, but they do show that 15 of the 16 respondents thought that the information on the range of topics covered was (very) useful. Feedback from the only respondent who did not find the pack useful shows that s/he questioned the assumption that PBS is the correct model.

The pack consists of five booklets and some thought the resources were not easy to navigate:

'Jumping from one resource to another is confusing and time consuming.'

'It is difficult to negotiate a way round these resources. The Competence Framework is very much like a textbook, would benefit from more accessible layout and pictures. Other sections suggest clicking to go forward but kept taking me back to the carers guide. Put the animation up front. The whole thing has good content but suffers from being like a daunting Hampton Court Maze! Suggest more follow on chapters rather than bitty sections of very different styles.'

There were also suggestions on how the content could be improved:

'A definition of "behaviour that challenges" early on would be helpful at times, as this can be subjective and may not capture all relevant parties. The support plan is great, but should be built into a more holistic support plan as there is the danger of it becoming just another sheet of paper, rather than an overarching one-stop document. The support it sets out should be central to the care plan rather than additional.'

There were also positive comments from survey respondents about the pack:

'I am already using it [the pack] to challenge services as an independent EbE doing Care Treatment Reviews in various settings and in the community with a lot of good feedback happening. Links given out to the PBS framework and quality leads lapping it up.'

'I know it is a lot of reading but there is lot of useful information that is of benefit to the carer for their loved one. Using the information will definitely increase the quality of life for their loved one.'

'All information very useful, the video was great and explained everything brilliantly.'

'I really wish this approach had been available when she was younger. She and we spent too many years wasted on blame/guilt - professionals allowing a blame culture to develop.'

Those who took part in the evaluation interviews were also generally positive about the PBS information

¹⁰ <http://pavingtheway.works/resource/tools-and-resources/>

pack. For example, professionals said that they recommended the resources to families as there was nothing else equivalent elsewhere, and the resources had been used in local events to promote PBS.

Most of the other resources available on the project website were seen as relevant to families, including the resources mentioned above and links to relevant resources on other websites. Both carers and professionals interviewed believed that the range of resources provided for families is unique and much better than what is available elsewhere (e.g. from local authorities). It was considered to be very important for families to have all the resources they need in one place and in the format they need it:

'As a parent I found that all the information I need is one resource, and the content empowers parents and gives parents the confidence to ask what they are entitled to.'

5.3 Disseminating learning

We have seen that the project was successful in delivering the range of planned outputs and the quality of its deliverables was reported to be consistently high and widely respected. In this section we consider how effectively the project learning was disseminated to key stakeholder groups.

Drivers of change and policy makers

While dissemination and influencing activities were planned mainly for the third year, the project started its influencing work right from the start, particularly at the national level as relevant opportunities emerged relating to the implementation of the SEND reforms and the Transforming Care programme. As illustrated in Box 3, the project has played a role in key national forum and processes. The evaluation findings suggest that the project:

- Gained visibility among national stakeholders and was seen as having the potential to make a difference through the provision of evidence and resources targeted at different audiences.
- Gained the support of government officials and was seen as 'speaking' with a unified and authoritative voice on early intervention for children with learning disabilities whose behaviour challenges.

Box 3 Paving the Way influencing activities at the national level

In 2013 project staff delivered a presentation to the **Transforming Care Programme** board, followed by a meeting with officials in 2014. In 2015 project staff reported that the Joint Improvement Programme (as the Transforming Care programme was previously called) formally recognised that change needs to begin early and established a children's sub-group informed by the project. In 2015-16 project staff were asked by NHSE to run events on delivering Transforming Care for children and young people. Project staff commented on drafts of the NHSE guidance Building the Right Support and were commissioned by NHSE to develop a guide on pathways for children and young people in collaboration with NDTi. The CBF CEO was part of the reference group that provided expert advice on the development of the new Service Model for commissioners of health and social care services.

In 2015 the **Children's Health and Wellbeing Partnership** board discussed a paper produced by the project about children in ATUs based on the Evidence Policy Briefing. The Board agreed to: identify relevant input from local education services into Care and Treatment Reviews (CTRs), with an education link to be invited to all CTRs for under 18 year olds in inpatient units; plan future improvements to the system to decrease overall admissions.

The project response to the **DH** consultation on **children's continuing care funding** was taken on board, and challenging behaviour was identified as a separate domain to consider for continuing care funding.

Project staff were part of the advisory group for the **DH guide on reducing restrictive interventions**. The guidance has been delayed within Government, and the project has co-ordinated a joint statement on reducing restrictive interventions from CBF, CDC, Mencap and the Children's Commissioner.

In summer 2016 Christine Lenehan, CDC Director, was asked by the Minister to review health and social care provision for children with learning disabilities whose behaviour challenges.

In 2015 project staff commented on the **DfE SEND code of practice**, while their input was not fully reflected in the code, recognition of the importance of local services post-Winterbourne was included. A review of the code of practice will take place in 2017 and CDC will propose that the code be revised to strengthen the messages about local support for children with learning disabilities whose behaviour challenges.

Some senior DfE officials have contributed to events organised by the project and DfE is leading on a work stream to ensure the education contribution to all CTRs for children.

The CEO of the CBF was part of the group that informed the development of the **NICE guidelines** on challenging behaviour and learning disabilities. The Evidence Policy Briefing was submitted to this group and helped to ensure that the guidelines included early intervention via parenting training.

There has been a high level of engagement with the **Learning Disability Professional Senate** with two presentations to the Senate in 2013, attendance at their conference and meetings throughout 2014-2016. In 2015 the Senate convened a national multi-disciplinary group focused on children with learning disabilities as a result of the case made by project staff. As indicated earlier (Box 2) the Senate and the project jointly produced an information leaflet on 'When children's behaviour challenges'.

There have been regular contacts with the **Office for Children's Commissioner (OCC)** since 2014. Project staff suggested revisions to an OCC report on residential schools which were taken on board. The Children's Commissioner has taken an interest in a young man in an Assessment and Training Unit (ATU) and has included ATU visits and data requests as part of the OCC work programme. The Children's Commissioner has agreed to speak at the APPG about ATUs and filmed a contribution for the March 2016 project conference.

Project staff have been in regular contact with the **LGA** and shared the Evidence Policy Briefing and Paving the Way guide. Project staff comments on the new service model were taken on board by the LGA.

Despite the project's efforts (e.g. share resources and arrange meetings with relevant people) there has been little engagement from **ADCS**, **Ofsted** and the **Care Quality Commission**.

Service commissioners, providers and professionals

A key aim of the project was to improve local services by influencing those responsible for commissioning and delivering these services. Figure 4 shows mechanisms used to reach this very large and diverse group, including:

- The project website which was redesigned, renamed (Paving the Way) and launched in spring 2016
- A national conference in March 2016 which was used to promote the project resources and tools
- Local events and consultancy:
 - project staff run two workshops, funded by NHSE, to discuss the new service model
 - a person centred approach to service planning and delivery will be promoted through the project's role in the consortium that secured a strategic partner contract with NHSE to support Individual Personal Budget (IPC) sites focusing on children with learning disabilities
 - project resources and its family contacts helped NDTi to deliver nine regional workshops on early intervention for children and young people
 - interviewees mentioned using the project resources in local events and training
 - project staff reported several requests to share the project learning at various conferences and events (e.g. the British Psychological Society child faculty conference, the Council for Disabled Children Members Meeting, a regional conference of the British Association of Community Child Health and a regional PBS conference) and there is now a PowerPoint presentation available on the website for this purpose.

Figure 4 Disseminating learning to service commissioners, providers and professionals



The evaluation findings show that these mechanisms for disseminating the project resources were viewed as effective. What it is much more difficult to determine within the scope of this evaluation is how many of the 1000s of people involved in commissioning and delivering local services were accessing the project resources.

Interviewees had very positive feedback on the **project website**, which was seen as providing very comprehensive and high quality resources. The evaluation findings are mixed on how widely known the project website and resources were. All those interviewed for the evaluation said they had accessed the website, planned to use it in future and had recommended it to colleagues and families. Similarly, three quarters of those who provided feedback on the national conference said they were planning to use the project website and resources and recommend them to others, while 71% had already used learning from the project in their work. The project web statistics show a considerable increase in traffic recently. Initially the project pages were hosted on the CBF website and over period of a year (January 14-February 15) the project pages had 2,044 visits (885 unique users), this compares with 16,457 visits (4,829 unique users) in

two and half months (mid March-end May 2016) after the new project website was launched. However, those interviewed thought there was low awareness of the project website and its resources, while they typically said they would not miss an opportunity to publicise relevant project resources, they could not think of colleagues who knew about the project and its resources.

The **national conference** organised in collaboration with the PBS Academy to publicise the project resources proved popular. It was attended by 60 delegates, the conference survey indicates that the largest group included practitioners (41%), with small proportions of family carers (18%), service commissioners (14%), policy makers (9%) and service providers (9%). Views on the conference plenary sessions and workshops were extremely positive, and the overwhelming majority of participants believed that the event had been (very) useful in providing a better understanding of:

- Where to get more effective support for children and adults whose behaviours challenge (91%)
- Effective intervention and prevention (100%)
- Challenges in accessing adequate support faced by children and adults whose behaviours challenge (100%).

Apart from the conference, there was no funding in the project budget to run other events, yet, as we have seen, project staff managed to secure funding from NHSE to disseminate learning through **workshops** on the new service model and through consultancies to IPC sites. The evaluation findings also suggest a 'trickle effect' with project resources used in local events run by other organisations, while the scale of this effect appears to be small at this stage, it has the potential to grow.

Finally, project staff are part of an academic consortium that has submitted a bid for a trial to evaluate Stepping Stones Triple P, a programme for parents with children with learning disabilities whose behaviour challenges. At the time of writing this report the outcome of this bid was not known, but if successful this project could greatly contribute to provide more robust evidence on the impacts of early intervention, with the potential for project staff to play an important role in disseminating this evidence.

6. Has the project made a difference?

The evaluation found that the project was implemented as envisaged in the logic model outlined in appendix 1: it delivered all the planned outputs, developed effective dissemination mechanisms and secured additional funding to build on the work it was originally funded to deliver.

There was no expectation that the long term project outcomes (i.e. improving families' access to local behaviour support using the PBS framework, ensuring better co-ordinated multi-agency responses, and more family involvement in co-producing services and local offers) would be realised within the project three-year timeframe. It was recognised by the project team that the kind of transformation in service commissioning and delivery needed to achieve these outcomes requires a longer timetable.

This evaluation has therefore focused on short and medium term project outcomes, achieving these was seen by the project team as a necessary precondition for achieving its ultimate aims. An assessment of the extent to which the project has achieved the expected short and medium term outcomes is based on the views of those who have been involved in the evaluation interviews and surveys.

Looking at **short term** outcomes first.

1. Learning disability policies to adequately cover children and young people. There is evidence that the project has achieved this outcome, as it was reported to have played a key role in shifting the focus of the post- Winterbourne discussions, with the project team playing a crucial role in drawing attention to the specific needs of children and to early intervention. It was felt that thanks to the efforts of the project the new service model is more comprehensive and has benefited from the project evidence on early intervention (e.g. it has helped to lower the threshold for intervention for some diagnoses). As one

respondent put it:

'The Transforming Care agenda opened the door to children and young people thanks to the efforts of the project.'

CBF and CDC were considered key to this success as they were seen as:

- Very influential (e.g. represented in key NHSE and DH meetings)
- Organisations government can work with because they are 'sensible'
- Having evidence to back what they say and being 'a force for good'.

2. Relevant children's policies to include accurate information on effective support for children and young people with learning disabilities whose behaviour challenges. It is more difficult to establish to what extent this outcome was achieved because there has been low engagement with the evaluation from relevant policy officials. From the limited evidence available it seems that while the project was highly regarded by relevant officials, it has had very limited influence. For example, project staff felt their comments on the new SEN code of practice were not fully reflected in the code.

Looking at **medium term outcomes**.

3. Increase awareness among professionals and commissioners of the needs children with learning disabilities whose behaviour challenges and their carers. While based on a small and selected group of people, conference participants who responded to the survey (Table 2) believed this aim has been achieved. Those who took part in the interviews also believed that a key project achievement has been to raise awareness of the needs of this group and provide a more accurate methodology for estimating its size. There is considerable evidence to suggest that the project has developed adequate resources and effective dissemination mechanisms to increase awareness, what this evaluation cannot assess is how many professionals and commissioners have been and will access these resources.

4. Develop examples of good practice that can be replicated to show what effective practice looks like. As shown in Table 2, those who responded to the conference survey overwhelmingly agreed that the project has played a key role in gathering and disseminating evidence of good practice, and in demonstrating that it is possible to overcome barriers and improve services. Similarly, 72% of those who provided feedback on the Paving the Way guide said that as a result of reading it they would definitely consider changes in the way they commissioned or delivered services to children with learning disabilities whose behaviour challenges. Comments from survey respondents illustrate the kind of action Paving the Way could prompt:

'This, along with the NICE guidance, has resulted in our service commissioning further multi-disciplinary team training in this area to support better assessment and implementation of behaviour management plans for children with learning disabilities.'

'I will be taking this document to our first Tender Group Meeting - we are only a very small community learning disability team and are under the CAHMS umbrella but I have a very loud voice.'

'I work in a CAMHS learning disabilities service and Paving the Way captured perfectly the approaches we aspire to use. It will be a helpful addition to our feedback to commissioners and will help us with the development of our existing services.'

There were also examples from the interviews of how the project resources more generally were used to influence local services. For example, they were used to:

- Make the case for preventative service
- Develop an impact statement showing the effectiveness of early intervention
- Develop project specifications with learning from good practice from other areas, and knowing what to avoid from the 'well trodden path'.

However, again we have no way of quantifying to what extent service improvement has been influenced by the project resources.

5. Enable family carers to ask for more effective support. As we have seen the views of carers and professionals who took part in the evaluation suggest that the project has created the right tools to enable carers to ask for more effective support. The project was also universally seen as a strong and effective advocate for families and as having given a voice to children and their carers. But again we do not know how many families have and will ask for more effective support with the help of the project resources.

Table 2 Views on the Paving the Way project’s achievements

	Strongly agree	Agree	Disagree	Strongly disagree
	%	%	%	%
Raised awareness about the challenges faced by children with learning disabilities whose behaviours challenge	62	38	0	0
Increased understanding of prevention and early intervention when working with children with learning disabilities whose behaviours challenge	52	48	0	0
Increased understanding of the role of evidence when working with children with learning disabilities whose behaviours challenge	48	52	0	0
Highlighted the value of using a Positive Behaviour Support Framework	57	43	0	0
Given a voice to children with learning disabilities whose behaviours challenge and their families	43	57	0	0
Encouraged more effective practice locally in supporting children with learning disabilities whose behaviours challenge	42	58	0	0
Provided resources on effective support for children with learning disabilities whose behaviours challenge	42	53	5	0

Source: Survey of conference participants (N=24)

7. Has the project provided good value for money?

Interviewees who had a good understanding of the project (e.g. were familiar with its plan and budget) believed that the project had provided good value for money. As one respondent put it:

‘They are a powerful force who punch well above their weight given their size and limited resources, they are often quoted nationally, making the voices of this group heard’.

Cost effectiveness was believed to have been achieved through the hard work and commitment of the project staff, as well as through pro bono work and effective partnership working.

The costs of some key project outputs were compared with approximate costs for similar outputs obtained from five charities to give an indication of whether the project has provided good value for money (Table 3). It should be emphasised that the comparison costs are very approximate, they are therefore indicative and should be interpreted with caution.

The view that the project has provided good value for money seems to be validated by comparing the costs of key project outputs with estimates of what it would have costed other charities to produce similar outputs. Predictably outputs that relied on considerable pro-bono contributions (i.e. the Evidence Policy

Briefing) and partner contributions (i.e. the PBS information pack and the conference) seemed to be particularly cost effective.

Table 3 Costs of project activities compared with estimates provided by other charities

	Project costs	Comparison costs
Evidence Policy Briefing	£5,200	£20,000-30,000
Video with messages from children and young people	£4,800	£3,000-5,000
Paving the Way guide	£7,400	£8,000-9,000
PBS Information Pack	£1,600*	£10,000-11,000
Conference	£2,700*	£5,000-8,000

* This excludes the contribution from the PBS Academy

Furthermore, the project could be seen as having provided good value for money as additional funding was obtained for dissemination and influencing activities, thus increasing the potential reach and impacts of the project outputs. For example, funding from NHS England to run workshops on the new service model and from the Transforming Care programme to develop local pathways for children and adults with learning disabilities (see section 5.2) will help to disseminate key project learning. Similarly, with funding to support Individual Personal Budget sites the project approach will be promoted locally (see section 5.2), and funding was secured from the Transforming Care programme to deliver parental training and develop a guide for parents (see section 8).

8. What does it all mean for children and their families?

Children and their families are the ultimate intended project beneficiaries. As noted earlier, it is too early to assess if the project has succeeded in ensuring they get more effective and better quality services reflecting their needs and wishes, and based on the evidence of what we know works.

While measuring these long term effects was beyond the scope of this evaluation, some findings do point to more immediate benefits for families from the project.

First, by placing children and their carers at the centre of its work, the project has enabled them to be agents of change rather than passive recipients of changes planned by someone else. This was evidently important for the individual carers who took part in the project activities, but it was also a powerful message as the project modelled the relationship they expect between families and services.

Second, it was widely believed that the quality, range and accessibility of resources available to parents are much better than before the project existed, and it is hoped these will reach carers who usually don't have the time and energy to make extensive searches, as well as the better informed families.

Third, the project team has secured funding from the Transforming Care programme to deliver training to carers. Early in 2016 in collaboration with Mencap the project team delivered training to equip parents with the skills and knowledge to reduce challenging behaviour. Later in the year it delivered 'Keeping in Touch with home' a guide to supporting children living away from home to keep in touch with their families, with a practical checklist for providers and commissioners.

9. What next?

There was concern among interviewees about what will happen now that the project funding is coming to an end, as it was believed that there is a need to keep up the momentum and the project resources need to become more widely known. More specifically interviewees believed that:

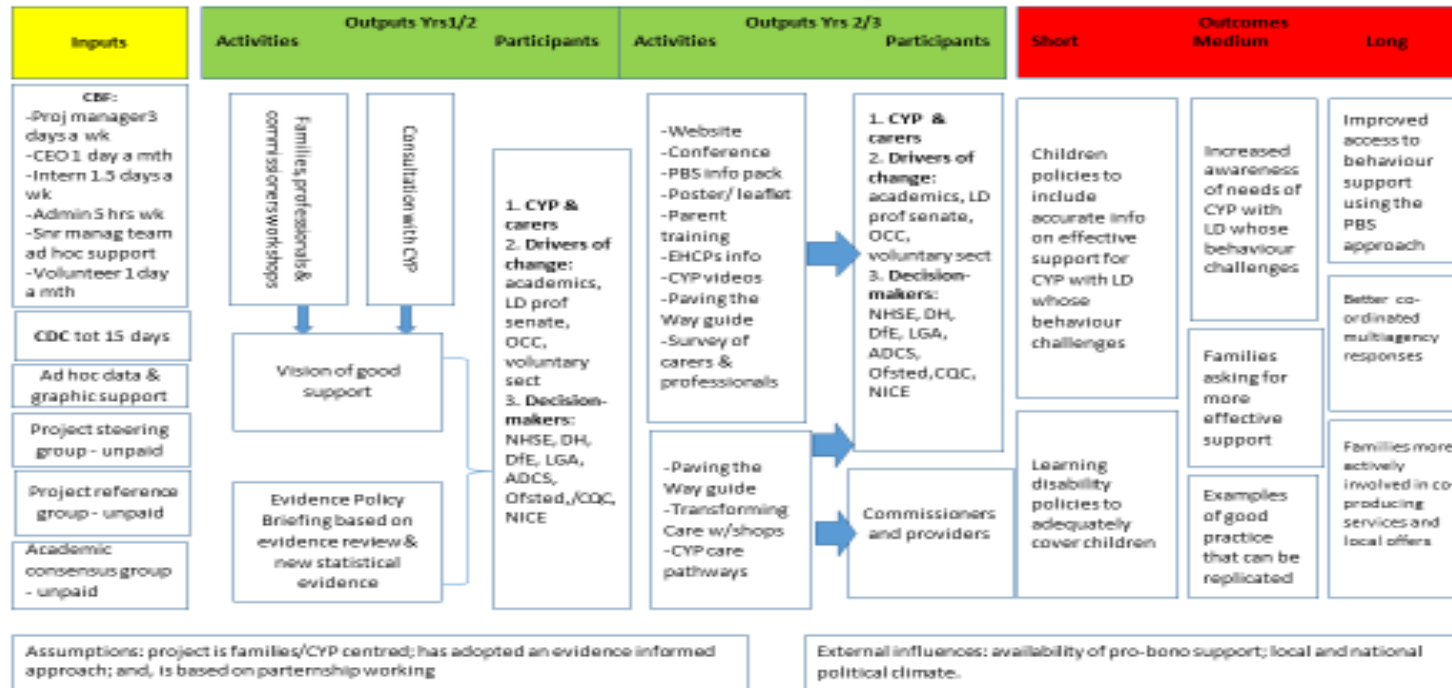
- Without funding to build on the work of the past three years the key messages so powerfully and persuasively put across by project staff may slide down the agenda and what has been achieved could be forgotten.
- There is a need to monitor if and how the project resources are used locally, what impacts they have, and how success stories can be replicated elsewhere.
- The project has not strongly tapped into local education provision and special schools in particular. It could, for example, establish links with a group of special schools to run a joint venture to share good practice locally with support from parents. CDC was seen having a crucial role in establishing more and better links with education.
- The project has an important role to play in training professionals (from health, education and social care) who work with children whose behaviour challenges and their families.
- There is a need to target mediocre commissioners, understand what would make these commissioners go out of their way and do something different. Two examples were suggested: a rolling programme of local events around the country targeted at early intervention strategic leads to raise awareness of the project approach and resources; working with a group of commissioners to understand their priorities and pressures, how the Paving the Way model would fit in the specific local context, what would they find useful and challenging and why.
- The project has effectively used the evidence to make the case for early intervention, it should now consider how that model can be extended into early adulthood.
- Developing resources for working with very young children (under two year olds) would also be extremely helpful.

The quote below from a parent summarises the strong feelings that emerged from the interviews about the need to 'keep up the good work' particularly in the current financial climate:

'It is hugely important to continue to make a strong case for adequate support for our children because our children are very expensive. Carry on the good work because nobody else out there is doing anything for our children.'

Evidence from the evaluation suggests that there is the determination and capacity to build on the what has been achieved by the Paving the Way project in the past three years. The CBF saw the project as being an integral part of their work. The project has enabled them to build an authoritative evidence base, develop some high quality and effective tools and resources, and provide a one-stop shop for families and professionals. The CBF wants to maximise the reach and impacts of the project outputs by fully integrating what the project has achieved into its organisational structure, for example, the project manager will continue to work for the CBF in a new role as their children policy lead, and, as we have seen, additional funding to promote the Paving the Way model was secured even before the project ended.

Appendix 1 Paving the Way logic model



Appendix 2 Evaluation methodology

Paving the Way guide survey

In spring 2015 the Paving the Way guide was sent to 100s of people responsible for commissioning and delivering children's services, including: Clinical Commissioning Group (CCG) commissioners identified from the NHS England website; a list of commissioners held by CDC; children's commissioners identified from the Local Government Association website; a list of heads of special schools held by CBF and CDC; a range of professionals on the CBF mailing list; and, key contacts in relevant government departments and agencies, including DH, DfE and NHS England. Shortly after the guide was circulated, an on line survey was carried out to explore views on the documents. The survey asked people who had been sent the publication: if it provided new learning on the challenges in accessing adequate support faced by children with learning disabilities whose behaviour challenges and on effective support for this group; how useful different aspects of the guide were; and, any actions taken after reading Paving the Way.

A total of 114 people took part in the survey:

- Respondents were mainly practitioners (64%), followed by providers/heads of children's services (23%) and commissioners (13%)
- Over a third of respondents (35%) were from the health sector, a quarter (25%) were from a local authority, the same proportion were working in the voluntary sector, while just under a fifth (19%) were from the private sector.

The PBS information pack survey

In spring 2016 an information pack for family carers was published and disseminated, and in May-June 2016 an on line survey was carried out to explore views on these resources. The survey was sent to members of the project's reference group which includes 34 family carers, 26 of these carers responded to the survey.

- The same proportion of carers (i.e. 31%) were caring for the following age groups: 11-16, 18-25 and over 25. 8% of respondents had children aged 5-10.
- Most respondents (88%) were caring for someone who was displaying behaviour that challenges, only three respondents said they were caring for someone who was at risk of such behaviour.

National Conference survey

60 people took part in the national conference in March 2016 and 24 (40%) completed the event evaluation form which explored views on the event and the work of the project. Those who completed the form:

- Were mainly practitioners (41%), with small proportions of family carers (18%), service commissioners (14%), policy makers (9%) and service providers (9%).
- Were mainly from the voluntary sector (43%) and health (35%), with small proportions from local authorities (9%) and academic/research institutions (4%).
- 48% worked with children and adults, 24% worked only with children, and 29% only with adults.