Valuing the views of children with a learning disability

Engaging with children and young people with severe or profound and multiple learning disabilities

The Challenging Behaviour Foundation

mencap
The voice of learning disability

Introduction

Who this resource is for

Anyone involved in supporting children with learning disabilities, including:

- Professionals responsible for developing Education, Health and Care plans for children with learning disabilities (EHCPs)
- Professionals conducting Care, Education and Treatment reviews (CETRs) for children with learning disabilities in hospital settings or community CETRs for children at risk of admission
- Transforming Care boards (who have a responsibility to engage children to inform their work)

Why this resource is needed

Children and young people across the country are often left out of decisions and processes that impact their lives. This is particularly true for individuals with learning disabilities and even more so for children with severe learning disabilities or profound and multiple learning disabilities. It is very unusual for children with severe learning disabilities to be asked to directly contribute their experiences to discussions about their wellbeing.

It is often assumed that children do not have anything to contribute if they do not have the capacity to understand complex problems. The need to use alternative methods of communication is also perceived as a barrier and the fear of challenging behaviour can lead to this group of children being excluded from consultation activities. This means that, within many organisations it is not a priority to ask children with learning disabilities what they think or how they feel in a way that truly values their contributions. Sadly, this includes some organisations whose decisions have a huge impact on the lives of children and young people with learning disabilities.

Challenging behaviour is often the only way a child with a learning disability or autism is able to express their unmet needs. The behaviour itself is a form of communication. However, all too often the response is to react to the behaviour itself, rather than to identify and address the underlying need. **Understanding the function of challenging behaviours is a key part of listening to what children have to say.**

Engagement leading to a better quality of life at school

A class teacher needed to understand why one of her students was running out of lessons and out of school. Her student had a severe learning disability and wasn't able to express his views verbally, so his teacher used Talking Mats to find out how he felt about class activities. Using Talking Mats he expressed that he didn't like it when the chairs were arranged in a line during the smart board activity. His teacher changed the layout of the chairs to a semi-circle which led to her student being much more settled in class.

Talking Mats

Meaningful engagement

It is not just 'good practice' to involve children and young people with learning disabilities in decision-making – the law (including the Mental Capacity Act 2005 and Section 19 of the Children and Families Act 2014) requires it.

The Special Educational Needs and Disability (SEND) Code of Practice (2015) says that "Local authorities must ensure that children, their parents and young people are involved in discussions and decisions about their individual support and about local provision."

To make this a reality, we need to actively hear what children with a learning disability have to say; both about their own lives and about the statutory services, settings, organisations and people responsible for supporting them.

Aim of this resource

This resource asks you to stop and think about whether you are doing enough to seek out the views and wishes of children with learning disabilities. It shows some methods which have been used to actively seek out the views and wishes of children with learning disabilities and signposts practical tools to help you in your efforts.

Thanks to

All the families who took part in the CBF's engagement project. Also thanks to Nick Gore, Suzi Scott, Jill Bradshaw, the Tizard Centre, Laura Ainsworth, The Communication Trust, Mencap, BILD, Barnardo's Link Plus, CAMHS NHS Pennine Care and Talking Mats.

We asked people to share their experiences of seeking the views of children with learning disabilities.

Sometimes this is called engagement, another term is participation. Whichever term is used, we mean actively enabling children with learning disabilities to share their perspectives in order to act on what they communicate.

Focus groups are a common method of engagement, but in our experience this is not always the best method for engaging those whose voices are rarely heard including children with severe learning disabilities, children with profound and multiple learning disabilities and children for whom speech is not their primary method of communication.

This resource therefore focusses mainly on examples of alternative methods, likely to be successful in reaching children often excluded from focus group engagement or consultation activities.

Examples of actively seeking children's views about:

1. What good support looks like, the CBF, page 6
2. Future goals, the Tizard centre, page 10
3. Decisions, Mencap page 12
4. School, The Communication Trust, page 14
5. Short breaks provision, Barnardo's Link Plus, page 16
6. Mental healthcare, CAMHS Pennine Care, page 18

Misconceptions

Have you ever said or heard any of the following?

"He doesn't speak so I can't ask him what he thinks."

"Children and young people can tell you what they think and feel in many ways and have a right to be heard. You need to find out which is the best communication method for him and learn how to use it."

"She doesn't understand what ... Transforming Care is/an EHCP is/an annual review is...so there is no point trying to involve her."

"The Mental Health Act Code of Practice (2015) says that children have a right to be involved in all decisions about them, even if they lack competence or capacity. Seeking a child's views and wishes will always help better decisions to be made about their education, care and support."

"I bring him to the engagement group/the meeting about his care - but he doesn't contribute anything."

"The Mental Capacity Act (2005) and the Care Act (2014) say that children and young people have a right to support to assist them with decision making, including communication appropriate to their needs and seeking the views of those close to them. Maybe he needs more help to contribute, or more imaginative methods used to seek his views. See guidance from the Council for Disabled Children and the Communication Trust about effective involvement of children with special educational needs or speech, language and communication difficulties in decision making."

"His behaviour is too challenging for him to be involved."

"Children with behaviours described as challenging have the same rights as all children to be heard. No one is too challenging to be listened to. Challenging behaviour itself is often communication of an unmet need, so understanding the function of behaviour can help to improve the way a child's needs or wishes are met. You need to understand how he participates and communicates, understand his behaviour support plan and tailor the engagement to suit him."

"We already have an engagement process, we've got it covered - we haven't missed anyone out..."

"Sometimes engagement processes which rely on speech based group sessions do not capture the views of young people with severe learning disabilities, profound and multiple learning disabilities or young people who display behaviours described as challenging. Does your engagement process capture the experiences and views of these young people or do you need to do more?"

"It's too expensive and difficult to involve children with complex needs, we don't have the budget or the skills for it."

"The Children and Families Act 2014 says that the views and wishes of children and parents should be at the centre of decisions about a child's education, health and care provision. Children with more complex needs have the same rights as all other children to be heard and for services to have regard to their views and wishes. Understanding their needs better will result in a better service. This does need to be properly resourced with skilled staff."

About profound and multiple learning disabilities (PMLD)[1]

People with PMLD:

- Have more than one disability
- Have a profound learning disability
- Have great difficulty communicating
- Need high levels of support with most aspects of daily life
- May have additional sensory or physical disabilities, complex health needs or mental health difficulties
- May display behaviours that challenge us

About severe learning disabilities

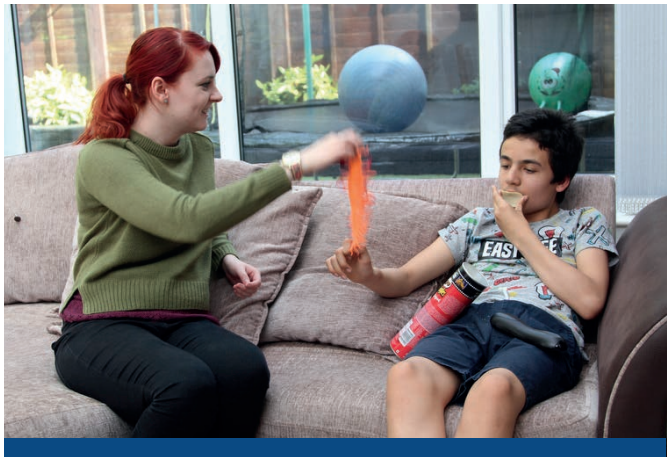
A child or young person with a learning disability will find it harder than other children to understand, learn and remember new things. He/she may need more support with everyday activities such as communicating, keeping safe and managing everyday tasks.

Someone who has a severe learning disability will:

- have little or no speech
- find it very difficult to learn new skills
- need support with daily activities such as dressing, washing, eating and keeping safe
- have difficulties with social skills
- need life-long support

1. PMLD Network definition - short version

1. The Challenging Behaviour Foundation: Finding out what good support looks like to children and young people



The children

Children and young people age 6-24 with severe learning disabilities and behaviours described as challenging, including young people with autism and complex health needs.

It is harder for children with learning disabilities to develop the communication and social skills which other children use to get them what they want and need. This may mean that their behaviours are much more challenging and they are unlikely to "grow out" of those behaviours on their own without skilled support to get their needs met in a different way.

Behaviours might be things like:

- Hurting others (e.g. hair pulling, hitting, head-butting)
- Self-injury (e.g. head banging, eye poking, hand biting)
- Destructive behaviours (e.g. throwing things, breaking furniture, tearing things up)
- Eating inedible objects (e.g. cigarette butts, pen lids, bedding)
- Other behaviours (e.g. spitting, smearing, repetitive rocking, stripping off, running away)

The purpose

To seek the views of children and young people about their support using alternatives to 'traditional' consultation (such as focus groups and interviews involving speech).

To demonstrate and share ways of consulting with this group to enable, support and inspire others to directly engage with children with learning disabilities and behaviours described as challenging.

Who carries out the engagement work?

A psychology graduate with experience of working with children with severe learning disabilities, trained and supervised by Jill Bradshaw, a Speech and Language Therapist and Nick Gore, a Clinical Psychologist from the Tizard Centre, at the University of Kent who also designed the methodology.

What we are doing

This project called "Stop, Look and Listen to me" was based on the Tizard Centre methodology (see p.10). It involves exploring the experiences and perspectives of children and young people with severe learning disabilities and behaviours

described as challenging. We are focussing on what good support means to young people.

Before the visit: A phone interview is carried out with a family carer or person who knows the young person well to ask questions about communication skills, support, activities, behaviour support and how the young person shows what they do and don't like. Based on this information the visit is tailored to the young person's communication needs (for example, sending a tailored information sheet to explain the visit, refreshing relevant Makaton signs, preparing symbols etc).

Visit: Children and young people are visited at their home or school. The person engaging with the young person spends time being in their environment and ensuring the young person feels comfortable in their presence and interacting with them. Four methods are used to gather the views and experiences of children and young people.

1. **1:1 Interview:** Children are asked four main questions using Talking Mats and a range of communication support individualised to the young person's needs, which may include symbols, photographs, Makaton signs, gestures, Now & Next charts and others. A mix of concrete and abstract ideas are included in the questions.
2. **Direct engagement in activities:** Activities are aimed at covering leisure, physical, learning, and self-help categories. Specific activities so far have varied depending on what the young person enjoys and what is practical within the visit, examples include: playing with various sensory toys, puzzles, art and craft, reading a book, trampoline, eating a meal and Intensive Interaction. Activities are video recorded for analysis after the visit.
3. **Observation:** Structured observations of the child or young person interacting with a family member or carer are recorded at regular timed intervals. "Observable indicators" (see page 8) are used to identify what the young person enjoys and engages with and what they don't enjoy
4. **Family carer questionnaire:** A follow up questionnaire is sent to family carers after the visit, to supplement the data gathered at the visit. Family carers are typically key advocates for young people with severe learning disabilities so their views are sought on their child's views and wishes as well as their own perspective.

What we have learnt so far

- Spending time with children and young people is invaluable in understanding their views and experiences, regardless of whether a Talking Mats interview is successful or not.
- By spending time with a child in their normal environment (at home or at school) you can build up a picture of their views and experiences based on direct engagement, observation and discussions with the people who know them best.
- Using individualised communication support, prepared before the visit, is extremely important in supporting the young person.
- The project is still ongoing and so we are still learning. Once "Stop, Look and Listen to me" is complete we will share our findings, what we have learnt and the methods used. See **www.pavingtheway.works**. Through sharing alternative methods of consultation we're hoping this will support and enable others to directly engage with children and young people with severe learning disabilities in the future and to inspire them to think of other ways of engaging.

What is Intensive Interaction?

"Intensive Interaction is a practical approach to interacting with people with learning disabilities who do not find it easy communicating or being social. The approach helps the person with learning difficulties and their communication partner to relate better to each other and enjoy each other's company more."

British Institute of Learning Disabilities

What are 'observable indicators'?

Observable indicators vary and are unique to each individual – we all show our feelings in different ways, and this is no different for people with severe learning disabilities. Although there are 'common' indicators of happiness or enjoyment such as smiling, this varies for each individual, for example some people smile when they are nervous.

For this reason, we asked family carers and people who know the individual well for observable signs (facial expressions, eye contact, interactions, speech or noises, body language, specific behaviours) the young person displays when they are happy, enjoying something, engaged, not happy, not enjoying something or disengaged. These are what we used to structure the observations to answer specific questions.

An example

Samuel's parents described some indicators of his happiness, enjoyment and engagement as: having a huge smile, laughing, making lots of eye contact with others, skipping around, jumping up and down, flapping his arms and hands, saying "happy know it" and singing songs. Some indicators of un-happiness and non-engagement identified were: crying, screaming in a high pitch, leaving the room, throwing items, stamping his feet, hitting his head with objects, saying "no thank you please" and "bye-bye".

Structured observation using these indicators showed that some of the things Samuel appeared to enjoy were: being on his swing, being visited at home, interacting with others (in particular when others repeated what he said, and laughing with him), having people's undivided attention, being sung nursery rhymes, eating, hugs with his parents and Intensive Interaction. He did not appear to enjoy: not being able to express that he wanted something or not being understood by others, waiting, not having a person's full attention and being asked to complete work at home.

2. The Goals and Outcomes for Intervention (Go-For-It Project: Finding out about children's goals for the future)

The children

The Goals and Outcomes for Intervention Project (Go-for-It) worked with children with a range of learning disabilities (including those with severe learning disabilities) and a history of behaviours that challenge. 14 young people participated with ages spanning 4-15 years.

The purpose

To find out children's views regarding how to improve the quality of their life.

To facilitate behaviour change, thinking about the interactions with those supporting the child, areas of strength and difficulty for the child and things they would like support to achieve in the future.

Who carried out the engagement work?

Dr Nick Gore from the Tizard Centre, at University of Kent, designed and led the project as part of a wider programme of work looking at how Positive Behaviour Support (PBS) can be used to improve the quality of life of young children and their families.

The scope

The child's own, specific needs and aspirations.

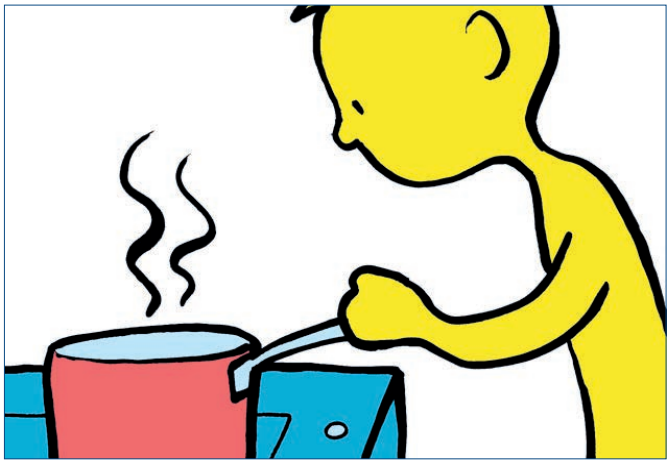
What we did

Children were engaged at a point when they and their family were waiting for service support, meaning that challenging behaviour was being displayed to a significant degree.

An initial session was conducted with children and families. The aims of this session was to:

- identify communication preferences
- agree proactive and positive strategies for reducing the likelihood of challenging behaviour within sessions
- agree reactive strategies to diffuse challenging behaviours and keep the child and others safe if these were to occur

Following this 1-2 interview sessions were arranged with children and young people. This and/or another session was also completed to build rapport with the child. Typically Talking Mats were used, with some adaptations to reflect the further specific needs of individual children. Topic areas included Quality of Life, different dimensions of the child's own behaviour and that of their parents and preferences regarding professionals and service support.



What we learnt

Preparation was key to tailor interviews and ensure a good working relationship with children – taking the family as the lead to support this.

The extent to which children could engage with question areas was variable but the **attempt to find ways to communicate with each child was greatly valued by families** regardless of this.

In each case the sessions provided direct contact with a child's needs and individual strengths and established a good potential foundation for future assessment and intervention work.

Children who used the Talking Mats provided some rich insights and ideas about their own support which would not have been known otherwise.

Nick Gore, Clinical Psychologist, Tizard Centre

Outcomes

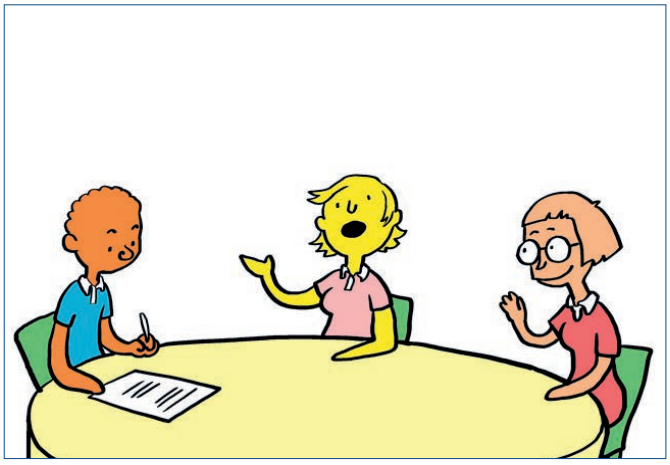
A clear demonstration that it is possible to interview children with learning disabilities about their interests, their own behaviour and that of others.

A protocol of questions and methods for interviewing children with learning disabilities, which was also adapted for use by the Challenging Behaviour Foundation in example 1.

An academic publication. Personalised and accessible feedback to families and young people to facilitate future behavioural support.

Advice to others

Individualisation is the key. Attempting to engage directly with children and young people is always of value and should be a priority for all professionals and services regardless of severity of disability or level of complexity.



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3. Mencap and BILD: Involving people with profound and multiple learning disabilities (PMLD) in decision-making

About Involve Me

Involve Me was a three year project about how to creatively involve people with profound and multiple learning disabilities (PMLD) in decision making.

The project focused on adults and young people, but the learning applies to children, young people and adults.

Who carried out the engagement work?

Communication facilitators

About profound and multiple learning disabilities (PMLD):

Most people with profound and multiple learning disabilities don't use formal communication such as words, symbols and signs. Many people with PMLD rely on facial expressions, vocal sounds, body language and behaviour to communicate. People need to use creative approaches to communicate with people with PMLD and help them share their preferences and what is important to them.

Purpose

To develop a resource - Involve Me – which aims to increase the involvement of people with PMLD in decision making and consultation. It shows how creative approaches can be used to ensure people with PMLD are given a platform to share what is important to them and be involved in, and able to influence, all types of decisions that affect their lives - from everyday decisions such as what to do, through to bigger decisions such as where they live, what services are developed in the local area, as well as government consultations about national policy. It is about ensuring people with PMLD are at the heart of decision-making.

What we did

Four sites took part in the project. A different creative approach to involvement was used at each one:

- Getting to Know You (Peer advocacy)
- StorysharingTM
- Creative Communication
- Multimedia Advocacy

There is information about each of these approaches in the Involve Me Evaluation report.[2] Four creative approaches were used in the project, but any creative approach could be used, as long as it puts the person at the centre, supports the person to express what is important to them and supports the person to share this with others.

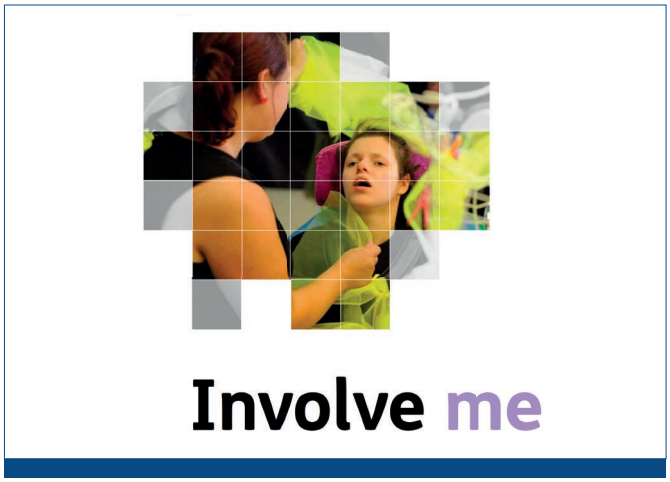
2. See Involve Me Evaluation report, Appendix 2 (Pg. 44-68): www.mencap.org.uk/advice-and-support/pmld/pmld-involve-me
For more information about the Involve Me project: www.mencap.org.uk/advice-and-support/pmld/pmld-involve-me

Here is an example of how Creative Communication was used to involve Tanya:

At one of the sites in the project, a sensory session was run for Tanya, a young person, focusing on some of the things they knew Tanya liked. It took place in a white room including feathers, lights and projected images of butterflies. Tanya liked the feathers, particularly when dropped on her from behind, giving an element of surprise. Some film was taken of the session and a sensory box was made, with butterflies and feathers, which Tanya can use to tell other people about her preferences.

Through the creative session it became clear that Tanya likes surprises. Staff are using what they have learned, for example in decisions around activities.

Case study from the Involve Me Evaluation report (edited)



What we learnt

Involve Me found that, whatever approach you use to involve people with PMLD, there are consistent messages about how to do this. Things like sharing interests, having fun, consistency, interaction and staff support are an essential part of the four approaches we looked at.

The learning from the project is summarised in the eight key Involve Me messages:

- Know the person well
- Take lots of time
- Don't make assumptions
- Be responsive to the person
- Be creative and try out new ideas
- Learn from what the person tells you
- Act on what you learn
- Help the person recall and share things about their lives

4. The Communication Trust: Finding out what children want at school

The children

Children and young people age 3-18 with moderate to severe learning disabilities with a mixture of speech, language and communication needs. For some young people their understanding of language was better than their use of expressive language.

Who carried out the engagement work?

A Speech and Language Therapist

The purpose

- To seek the views of children with speech, language and communication needs
- To develop a resource (Involving children and young people with SCLN: A toolkit for education settings. The Communication Trust)
- To support schools to deliver the participation required under the SEND Code of Practice.

The scope

The engagement demonstrated is a key principle within the national SEND reforms.

The children and young people involved were asked about individual and school level issues.

What we did

The work took place mainly in two special schools and also with some children in mainstream schools. We supported schools to:

- Consider what systems they had in place to seek the views, wishes, and feelings of children
- Think about what individual children or young people understand and how they communicate
- Use this knowledge to inform the approach used for each individual and to improve school practices

Improvements included:

- Demonstrating Talking Mats to school staff (a useful way for children with moderate to severe learning disabilities to share their views) and other communication methods
- Development of one page profiles for each pupil, showing what is important and interesting to them and their preferred methods of communication
- Supporting a change of mindset, helping staff get used to the idea that children have

something to say and supporting them to develop the skills to listen (e.g. expect a response, wait, allow processing time)
- Much greater use of signs and symbols embedded within school corridors, classrooms and documents

What we learnt

- What was important to the children and young people. This was different for each individual, for example with some children identifying a wish to make friends and a need for support with that, other children and young people indicating a desire to develop cooking skills and others with an interest in music, to include a few examples. These were things that had not been identified within schools before, but once identified, school was able to help make a difference
- The scale of the challenge to deliver on the statutory requirement for the children's workforce to seek the views, wishes and feelings of children and young people

Change needs to occur in three key areas:

1. **Culture.** A recognition that participation should be a key part of any children's setting.
2. **Skills and knowledge.** Staff need the communication skills and understanding of learning disability and autism to effectively seek the views of this group of children. They also need the time to do this properly.
3. **Leadership and accountability.** There is a need to remove the barriers which stop schools investing in engagement. Participation will help to improve the school experience for children and staff but it is hard to implement when it is not supported by the leadership and accountability processes within the school and the wider system.

Outcomes

A significant change in practice to embed participation within one special school.

Changes to the way individual children or young people were supported – e.g. a young man was given the opportunity to DJ in school leading to a much more constructive relationship with school as a whole.

Advice to others

The work we have done provides a model of engagement but requires additional capacity (expertise, training, time) to allow others to replicate it. It should be led by professionals who have the right expertise (likely to be CAMHS, Educational psychology or Speech and Language Therapy).

5. Barnardo's short breaks and fostering service: Ongoing involvement of children and young people to influence their short breaks service

The children

Disabled children and young people with a range of complex needs, including behaviour that challenges, health and physical needs and a variety of communication impairments. The majority of young people use augmentative communication systems.

Who carried out the engagement work?

Supervising Social Workers and Home Support Coordinator, Service Manager and Team Manager

The purpose

To develop a personalised, dynamic and interactive method for young people to provide feedback on the service.

What we do

- The Disabled young person/child is accompanied by a parent or carer who is able to support with health and communication needs
- We have a loose framework for the session that can be adapted and personalised to individual need and communication systems
- There is a high staff ratio to undertake "behind the scenes" tasks (refreshments, Health and Safety etc.) as well as helping to facilitate the session, assist with direct work and observation/evaluation
- The session usually commences with a focused, time limited piece of work relating to the participation subject followed by a "fun" workshop. For example we used a choice board with images supported by Widget and asked the children/young people to select the main ingredients for making a good short break. The children enjoyed selecting Velcro backed choice cards and placing them in the pot and mixing the ingredients up with a wooden spoon.
- We usually have an overall objective for the focus of participation but within this the young people are encouraged to set the agenda e.g. a group of teenagers compiled a number of questions to ask within a "vox pop" session
- Other methods of engagement have been to have the voice of the child represented in the recruitment of staff by having a Carer supporting a young person to be involved in an interview process; having questions from young people as part of the interview process where they are unable to attend in person; and producing a DVD Children's Guide that can be shown to newly referred young people.

What we learnt

We have learnt a great deal from the young people about what they want from their Short Breaks.

We also worked with the children to find a new name for the group and one member came up

with the great suggestion of “We can do it!” The children also selected the focus for the next session which was a sports related event.

As a staff group, we have also learnt a great deal about what works and what is less successful in participation and have been able to share this learning with other organisations and communities of practice.

Advice to others

- Be realistic in what is achievable and don’t feel overwhelmed by where to start: small steps are worthwhile and valid
- Gain an understanding and appreciation that participation can be interpreted at various levels and that there is no hierarchy of participation
- Keep going - view participation as integral to service delivery and development and not a separate activity

Outcomes

We have clear feedback on the short breaks service from children and young people.

We have developed direct work skills and formulated a range of creative methods to engage with and capture the Voice of the Child. As Supervising Social Workers we are more attuned with individual needs of the children and young people and which enables us to observe their progress in placement and ensure good outcomes.

Parents, Carers, children and young people have been able to come together and reduce social isolation, gain confidence and to participate in a fun activity.

It has enabled us to raise the profile of Disabled young people and children within the local community, for example through relationships with Participation Partners and also through events such as an Art exhibition in the City Library showcasing what Short Breaks means to young people. This has in turn promoted greater inclusion and understanding of the needs of Disabled children/young people in the wider community.

6. CAMHS Team, NHS Pennine Care: Making sure that children and young people's views are at the centre of their mental health care

The children

Children with moderate to severe learning disabilities or autism and behaviours described as challenging

Who carries out the engagement work?

Clinical Psychologists

What we do

Before training in Talking Mats, the CAMHS team was developing a comprehensive care pathway for the Positive Behaviour Support approach to challenging behaviour.

As part of this, the team described that holding the young person at the centre of all the work we do to allow them to achieve their potential was a fundamental value.

As part of the care pathway, we looked at how the young people we work with communicate their needs through their behaviour and we need to 'listen' appropriately to allow them to reach their goals without the need for behaviour that challenges.

We agreed that Talking Mats provided a means to have the actual voice of the young person heard, not just what they were able to communicate through behaviour. That immediately struck us as an essential aspect of this pathway. We still work to understand behaviour but now have a complimentary resource that allows us to hear from young people directly and work in a way that places their voice at the centre of the whole assessment and intervention.

The outcomes

Across the team, we have seen very tangible and real benefits. We are engaging young people far more in our interventions. Young people with significant communication and mental health needs are more directly involved in their care. Positive Behaviour Support plans are made more collaborative and the voice of the young person can be shared with parents, school or respite to benefit the lived experience of the young person.

We are doing more direct therapeutic work with young people where in the past we have worked more systemically.

We are also able to complete assessments relating to the Mental Capacity Act more efficiently.

Making it Happen

We asked all the contributors to this resource to identify what they learnt from their experience of engagement and what advice they would have for others. From those contributions we have identified four areas to address in order to successfully engage children and young people with learning disabilities:

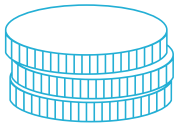
Culture

For too long the views of children with learning disabilities have not been valued. Seeking the views of children should be an integral part of working with children and young people with complex needs, not an added task. Many organisational cultures struggle to see engaging children and young people as a core part of their everyday business. Where they do so, the tangible improvements are clear.

Skills

All of the examples shared have highlighted the importance of using the communication method preferred by the child and having an understanding of the functions of their behaviour. Working with harder to reach groups requires skills and experience and engagement should be led or informed by someone who knows the individual well.

Funding/resourcing



Most of the resourced projects were voluntary sector or research funded. Those statutory services involved saw engagement as a core part of their "day job" – a key part of the service they run. There is no additional funding to help schools, CAMHS services, or social care to engage children and young people, despite the legal duty to do so. This lack of funding presents additional challenges to engaging with children with severe learning disabilities, especially given that this engagement or participation will need to be carefully planned and individualised to each child, as demonstrated by the examples.

Time

Engagement can't be rushed to meet external deadlines although this is often the context in which it takes place. It should be an ongoing process to inform an individual's care and support and to feedback strategic messages to wider services.

5 reasons to prioritise engaging with children and young people with complex needs

It's a statutory requirement. The Mental Capacity Act (2005), Children and Families Act (2014) and SEND Code of Practice (2014) all make clear that children and young people must be involved in decisions about their lives.

It's the right thing to do! Children and young people should be able to make choices about their own life – this can improve mental wellbeing, reduce behaviours that challenge and allow a child or young person more independence.

It leads to better care and support. Support staff and family carers can feel more confident when supporting an individual if they can find out how that individual would or would not like to be supported.

It encourages partnership working. Engagement and participation help to foster a culture where children and young people, family carers, schools/colleges, support providers etc. are all working together.

It improves communication. Exploring different engagement activities provides opportunities to explore a range of communication methods, this is especially valuable as children are often only offered one alternative method of communicating.

Useful Links

Communication

1. Talking Mats www.talkingmats.com
2. Communication Toolkits www.thecommunicationtrust.org.uk/resources/resources/resources-for-practitioners/involving-cyp-with-slcn-toolkit
3. Involve Me (Mencap & BILD) www.mencap.org.uk/advice-and-support/pmld/pmld-involve-me
4. Other Ways of Speaking www.thecommunicationtrust.org.uk/media/3414/other_ways_of_speaking_final.pdf
5. Challenging Behaviour and Communication information sheet www.challengingbehaviour.org.uk/understanding-behaviour/communication-sheet.html
6. Intensive interaction http://usinabus.org.uk/what-we-do/intensive-interaction/
7. British Institute of Learning Disabilities (BILD) factsheet about Intensive Interaction, www.bild.org.uk/resources/factsheets
8. Communication passport www.mycommpass.com
9. What works in communication – library of evidenced interventions. www.thecommunicationtrust.org.uk/projects/what-works/what
10. Raising our Sights how-to guide: Communication for people with profound and multiple learning disabilities www.mencap.org.uk/sites/default/files/2016-06/2012.340%20Raising%20our%20sights_Guide%20to%20communication_FINAL.pdf

Decision making and capacity

11. Mental Capacity Act information & IMCAs https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice
12. Decision Making Toolkit: A practical guide to supporting young people with special educational needs and disabilities to make their own decisions and to be involved in the best interests decision making process, The Council for Disabled Children councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/Final%20Decision%20Making%20Toolkit.pdf
13. Exploring the involvement of children and young people with SLCN and their families in decision making - a research project. The Communication Trust www.thecommunicationtrust.org.uk/resources/resources/resources-for-practitioners/involving-cyp-with-slcn-research

Challenging behaviour

14. Challenging Behaviour Foundation Information sheets www.challengingbehaviour.org.uk/understanding-behaviour/understanding-behaviour.html
15. Early intervention for children with learning disabilities and behaviours described as challenging www.pavingtheway.works

Education, health and care plans (EHCPs) and Care, Education and Treatment reviews (CETRs)

16. Information sheets on EHC plans for children with learning disabilities and behaviours described as challenging pavingtheway.works/whats-new/ehcplans
17. Care, Education and Treatment Reviews guidance (CETRs) www.england.nhs.uk/learning-disabilities/ctr/my-ctr

Engagement/participation

18. Paving the Way – What Children and Young People Enjoy pavingtheway.works/resources/children-young-people-enjoy
19. Council for Disabled Children (CDC) participation guidance and resources (from CDC and other organisations)
    councilfordisabledchildren.org.uk/our-work/participation
    councilfordisabledchildren.org.uk/transition-information-network/information-and-support/participation

The Challenging Behaviour Foundation

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