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***“Stop, Look and Listen to me”:*
engaging children and young people
with severe learning disabilities**

February 2021

Stop, look and listen to me

Summary

This report summarises the work we (the Challenging Behaviour Foundation and the Tizard Centre) did to find new ways of “asking” five young people with severe learning disabilities (whose behaviours are described as challenging) what they enjoy and who or what supports them to do those things.

We were able to find out information about what the young people enjoy (and what they don't) in a range of ways and our mixed methods approach allowed us to gather rich information from each young person in answer to our questions.

We found that family carers, advocates and staff who knew the young people well were key to seeking their views and perspectives successfully. Their role included: preparing our researchers with information about communication methods, observable indicators of enjoyment and behaviours that indicate the activity should be stopped. They also had a key role in supplementing the information we gathered from and with the young people themselves with more abstract information about the support available to young people to access enjoyable activities.

We would like to see all commissioners and providers of support for children and young people with severe learning disabilities taking active steps to seek their views and preferences directly on a regular basis. We would also like to see all consultation processes relevant to disabled children and young people adapted to include a strand which is accessible to young people with a severe learning disability.

We hope this small scale, unfunded piece of work will be a first step towards developing new and better ways to seek the views, wishes and perspectives of people with a severe learning disability (of all ages) and that such engagement becomes par for the course, rather than an unusual and innovative project.

Introduction

Everyone has the right to have their voice heard. However, the Challenging Behaviour Foundation (CBF) hears far too often from families who say their child has been excluded from consultations about services which directly affect their lives, even where there is a legal obligation to listen to their views (for example, section 19 of the Children and Families Act 2014).

This situation is not acceptable. When young people's behaviours challenge, often they are trying to tell us to "*Stop, Look and Listen to Me*".

This report contains the results of our "*Stop, Look and Listen to Me*" project, developed with the Tizard Centre at the University of Kent, to seek the views and experiences of children and young people with severe learning disabilities up to the age of 25.

The project aimed to explore and develop alternative methods of consultation and to demonstrate that it is possible to engage with children and young people with severe learning disabilities. The methods used were based on prior approaches used by researchers at the Tizard Centre (Bradshaw, Gore, & Darvell, 2018; Gore, McGill, & Hastings 2021).

We wanted to find out the answers to two questions from the young people:

- What do you enjoy doing?
- Who or what supports you to do the things you enjoy?

The overall project was unfunded, though some individual visits were funded to inform specific consultations. The project therefore took place over four years, between 2016- 2020, with visits taking place 2016-2018 and report writing when staff capacity allowed.

Who took part?

As part of the "*Stop, Look and Listen to Me*" work, we consulted five young people with severe learning disabilities. All young people's names have been changed for the purposes of confidentiality.

1. David was 12 years old and lived in the South East of England when the engagement visit took place. He has a diagnosis of a severe learning disability, autism and Attention Deficit Hyperactivity Disorder (ADHD).
2. Jaden was 14 years old and lived in the South West of England when the engagement visit took place. He has a diagnosis of a severe learning disability, autism and sensory impairment.

3. Emily was 22 years old and lived in Lancashire when the engagement visit took place. She has a diagnosis of Cardiofaciocutaneous syndrome; an atypical form characterised by complex epilepsy, a severe learning disability and autism.
4. Opeyemi was 18 years old and lived in South London when the engagement visit took place. He has a diagnosis of a severe learning disability, autism, epilepsy and Down syndrome. He is visually impaired and has poor hearing and gross gastrointestinal disorders.
5. Akeelah was 19 years old and lived in London when the engagement visit took place. He has a diagnosis of a severe learning disability, autism and epilepsy.

The young people were from five different Local Authorities areas across England. They were all reported as having displayed behaviours described as challenging. Their family carers and some of the professionals that support them were also involved in the engagement.

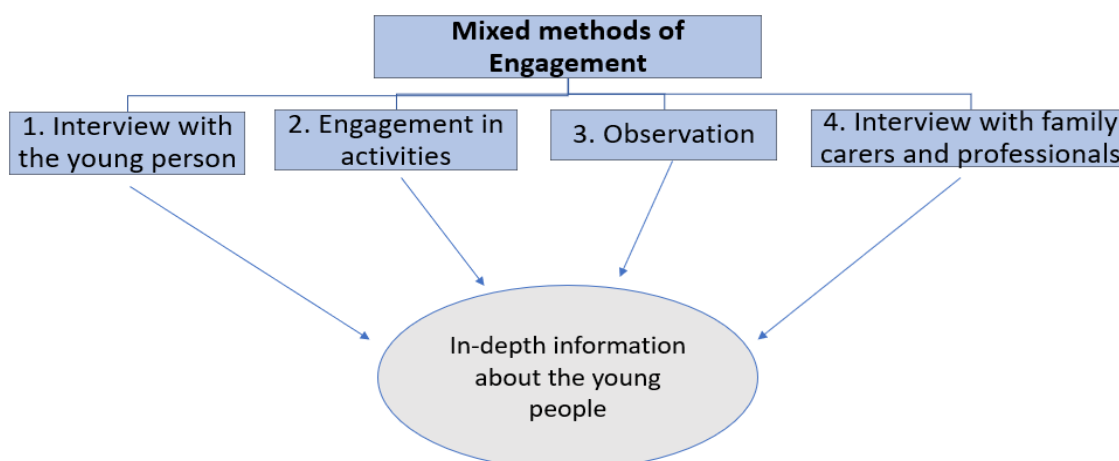
David and Opeyemi were visited at their family homes, Jaden was visited at the residential school he attended (a specialist school for people with a diagnosis of autism), Emily was visited at the specialist residential centre for people with complex needs where she lived, and Akeelah was visited at the school he attended.

Consideration was taken around the capacity of all young people to consent. As David and Jaden were under 16 years of age their parents gave assent for their participation. As Emily, Opeyemi and Akeelah were over 16 years of age, an independent panel assessed whether their participation was in their best interests, in addition to consent from their family carers.

Prior to each visit, family carers were asked how the young person communicated if they did not want to do something or how they expressed feelings of distress (any body language, behaviour, speech etc.). The engagement was stopped if any of these indicators were shown during the visit.

Mixed methods of engagement

We used a mixture of methods to maximise engagement with the young person, starting with a direct interview, engagement in activities, observation, and finally an interview with family carers and/or professionals who knew the young person well. The methodology was specifically developed by the CBF and the Tizard Centre for this project, based on previous Tizard Centre research (Bradshaw, Gore, & Darvell, 2018; Gore, McGill, & Hastings 2021).



1. An interview with the young person: This involved asking the young person questions supported by Talking Mats®, a communication tool which uses symbols to support people with communication difficulties to express their views on various topics. Interviews were tailored to the young person’s communication needs and included an additional communication support such as gestures, facial expressions, Makaton signs and symbols to support the young person. This method did not work for all participants as it requires a level of symbolic understanding which is not possible for all young people with severe learning disabilities.

2. Engagement in activities: To gain the perspectives and experiences of the young people where an interview was not successful (or to supplement the interview), the young person was directly engaged in activities based on their interests and abilities, such as playing with toys, art and craft, completing puzzles and so on. This was video-recorded and analysed following the visit.

Observable indicators (see box below) of the young person’s enjoyment or non-enjoyment were used to help understand the young person’s perspectives and experiences. Observation sheets were completed to look at what the young person appeared to enjoy and not enjoy based on these ‘observable indicators’. This was completed by looking at the things that happened before (the “antecedents” to) the young person displaying one of their ‘observable indicators’.

What are observable indicators?

Observable indicators are observable signs (body language, facial expressions, interactions, speech or vocalisations, behaviours etc.) a person displays that express their feelings. Although there is some similarity between ways people express enjoyment, this can vary and is unique to each individual, for example some people smile when they are happy whereas other people smile when they are nervous.

Asking family carers to identify observable signs of when their child is: enjoying something; not enjoying something; engaged; or disengaged reduced subjectivity in the analysis. For each young person, family carers selected up to five key indicators of enjoyment and engagement, and up to five key indicators of non-enjoyment and disengagement.

3. Observation: The young person was observed engaging in activities with their family carers or staff who support them. Observation sheets were completed at timed intervals based on the observable indicators of enjoyment, non-enjoyment, engagement and non-engagement.

4. Interview with family carers and professionals: Prior to the visit the family carer was asked questions around the young person's:

- receptive communication (understanding others),
- expressive communication,
- observable indicators,
- activities they enjoy and do not enjoy and
- behaviour support (for example any challenging behaviours they may exhibit and how to minimise any distress which may lead to behaviours that challenge).

This information was used to prepare the visit (e.g. tailoring communication to meet the young person's needs, preparing materials for engagement activities, preparing an information sheet for young person).

A follow up interview for family carers was then conducted. The parents of the young people completed a questionnaire after the visit. This was used to supplement the information gathered at the visit and to seek further information.

What we found out

Using the mixed engagement methods, we were able to find out a lot of in-depth information about the young people we visited.

All the young people were able to indicate what they enjoy/do not enjoy

Akeelah was able to tell us what he enjoys using the Talking Mats interview. He and all the other young people were also able to show us what they enjoy, either when we were engaging in activities with them, or observing them.

David

David showed happiness and engagement by smiling, laughing, looking at others and making eye contact whilst flapping his arms. We saw him demonstrate all these observable indicators, particularly when playing on the trampoline with his brother.

The four main observable indicators of unhappiness or disengagement for David were: screwing up his face, making a grumbling low pitched sound, biting his arm and going between different activities frequently. He demonstrated some of these during his dinner time when he did not appear to like the taste or texture of his food.

Jaden

The observable indicators of enjoyment for Jaden were: smiling, giggling, jumping about, asking for tickles and not moving away from the person or activity he is engaged with. We saw these demonstrated when re-watching his favourite sections of videos and during a yoga session with his Teaching Assistant supporting him to try yoga positions.

Jaden showed he was unhappy by saying “no thank you”, closing his eyes, moving away from a person or activity and displaying aggression towards others.

We saw some of these indicators from Jaden when people he didn't know well were in his surroundings, when he was denied a request to go on the computer and had to wait, and when he was asked to do physical activity before going on the computer.

Emily

During our visit, Emily was able to indicate her enjoyment in a number of ways, including

- By accepting the activity being offered or initiating it herself, for example, putting some pieces in the musical jigsaw, going into the lounge at the other end of the building to listen to music);
- By rocking slightly and vocalising (for example, when smelling her sensory box items);
- By sitting on her bed and bouncing (for example, when smelling the coffee or oregano from her sensory box items);
- By softly vocalising (for example, when watching Teletubbies);
- By moving her fingers rapidly for a short time (for example, when listening to music)

Emily was able to indicate that she did not want to engage with an individual by gently pushing away the outstretched arm of the individual but did not, according to the staff supporting her, appear to be anything other than relaxed and calm when doing this during our visit. Emily was also able to terminate an activity (for example, by getting up and walking away) or by handing items back to the person.

Opeyemi

Opeyemi showed happiness by: smiling, making a high pitched noise, giggling, jumping up and down, flapping his hands, kissing his mum, rubbing his feet together, stimming (though he also does this when anxious) and flapping items together.

We saw these when Opeyemi was playing with a toy (small soft pirate tactile toy), and during interactions with his Mum.

When Opeyemi was unhappy he put his thumb in his mouth, looked down at the floor, made low pitched grumbling noises, pushed people away or hit them with a toy he was holding. When bored he walked away or put his hand in his mouth.

We saw these indicators when a care worker got very close to Opeyemi and looked him right in the eye and when he was asked to sit down while waiting for his lunch.

Akeelah

Akeelah showed happiness with a smiling facial expression, making eye contact, singing along with music, running around, dancing, holding others hands, laughing, looking in the mirror, twisting his own hand, standing up and down, moving his mouth around and finishing the task he was focused on.

Some of the things he appeared to enjoy and engage with were playing a game of Connect 4 with other students, doing high fives afterwards and being supported to use Now and Next charts.

The observable indicators of boredom and distress included: covering his ears, folding his hands, making a 'yeahhh' sound, playing with his fingers, repeatedly leaving (or asking to leave) the room (e.g. multiple toilet visits), walking away, yawning, resting his head on the table and sleeping.

These were observed at a number of points during the visit, including when school work was presented in a way that Akeelah did not appear to understand or was confusing (e.g. the communication style of work tasks appeared to confuse and overload him, with questions presented in complex ways with multiple words, limited processing time, rephrasing questions quickly, unclear instructions - primarily verbal).

Of course, some activities may be consistently enjoyed while others may depend on mood or other circumstances, so the findings above do not give us a fixed picture of what the young people we visited enjoy, but it does give us a window into a better understanding of what they may and may not enjoy and a good starting point to explore this further.

Formal communication (e.g. speech, signing) is not necessary and there are other ways of gaining information directly from young people about preferences

This will be an obvious finding to family carers or those experienced in working with people with severe learning disabilities, yet it remains a common misconception that a lack of spoken language means someone is unable to communicate.

As set out in the section above, we were able to gain information from and with all the young people we visited about whether or not they enjoyed the activities they were engaged in. By taking time to understand the observable indicators of each individual with a severe learning disability and then watching carefully for those

indicators in different situations, we gained a much better understanding of what people enjoy and don't enjoy.

In addition to the observable indicators we also collected as much information as possible about each young person's receptive and expressive communication.

David

David understands some speech spoken to him, specifically simple language within his routine around 2 key words. He does not always understand abstract concepts. Makaton signs, photographs, gestures within context, facial expressions and sometimes symbols support his understanding.

The main way David communicates is using Makaton signs, he will also take a person to something he wants or needs help with, and sometimes he will point. He makes some vocalisations, but these are not recognisable as words, the pitch does change depending on mood.

Jaden

Jaden understands some speech – up to two key words with lots of support from the context or situation he is in. Gestures, symbols and photographs help his understanding. He struggles with abstract concepts and language regarding things that are not physically there.

Jaden uses some speech to communicate. He uses words that he sometimes puts into sentences, which are understandable mostly by those who know him well. He has used symbols at school and also makes eye contact, points and chooses from items.

Emily

Emily needs time to process information. She is able to understand basic commands with support from the context and situation is really important to help her to make sense of what she is being asked to do, not just the words. Some objects are used with Emily, along with a book which contains photographs and some symbols. She finds photographs easier to understand than symbols.

Emily communicates and interacts using eye gaze, pointing, Objects of Reference (e.g. getting her shoes if she wants to go for a walk), tapping an item if she wants it or pushing it away if she doesn't and vocalisations.

Emily does not use either signed communication or picture exchange systems such as Picture Exchange Communication System (PECS). She is therefore reliant on other people to skilfully interpret her communication.

Opeyemi

Opeyemi understands some speech – perhaps one key word in a sentence with a lot of supporting information from the context. Gestures and signs help his understanding. He has a limited understanding of symbols and photographs and does not understand abstract concepts. Opeyemi has hearing loss so things need to be said loudly and it helps to go close to him, take his hand and say his name in order to get his attention.

Opeyemi makes some vocalisations. These are clearly differentiated (especially for those who know him). Opeyemi will take people to items he wants and point with his eyes. He has used PECS at school.

Akeelah

Akeelah understands verbal questions but struggles with abstract language or concepts. Akeelah also understands some Makaton signs (e.g. colours, activities). On his communication iPad he has several symbols which he understands. Visual aids support his understanding (e.g. pictures, symbols, signs).

Akeelah does not use any spoken language. He uses a communication iPad (with pictures and symbols) to make choices from 2-3 options. The pictures and signs on the iPad are colours, shapes, places to go to, activities etc. He sometimes needs prompting to use the iPad. He can sign but does not sign usually (apart from 'toilet' 'yes' and 'no'). The best way to ask him his views will be to ask him questions with options for him to choose.

Children with learning disabilities often have difficulties with developing receptive and expressive communication, need support to develop communication skills and use a range of alternative methods of communication to speech.

Children and young people with severe learning disabilities often have little or no speech. This should not stop people seeking their views; instead the onus is on us to understand the best way of seeking the views of each individual.

Family carers, advocates and staff who knew the young people well were key to this project

We found that family carers, advocates and staff who knew the young people well were key to seeking their views and perspectives successfully.

Preparation

Before each visit, researchers spoke to family carers or others who know the young person well to make sure they had comprehensive information about each young person's receptive and expressive communication abilities, preferences and communication methods used. A key part of this discussion was to ensure that researchers were aware of any behaviours which might indicate distress or that the activity should be stopped. It was a clear principle of the project that if the young person indicated they did not want the researcher present the visit would end immediately. Researchers also asked those who knew the young person well to identify the observable indicators.

Some of the observable indicators may have been understood as enjoyment or by anyone watching, e.g. smiling, laughing, eye contact. Some indicators that young people were not enjoying things may also have been quite clear e.g. walking away from an activity, putting hands over ears. However, other indicators were much more subtle and unique and would be very difficult for someone unknown to the individual to recognise without input from someone who knows them well e.g. the

particular pitch of vocalisations, stimming, use of a phrases such as “yeah” to mean stop etc.

More complex or abstract information about support

Some of the individual consultation visits were conducted to inform specific policy development (for example the NHS Long Term Plan). To help answer more complex questions about support which directly related to the NHS Long Term Plan it was necessary to supplement the information provided directly by young people with information from those who know the young person well. It is important to clarify that this was not prioritised above directly seeking the views and perspectives of young people, but was a way of gathering contextual information which added weight to what young people communicated themselves.

For example, we found that Jaden enjoys swimming and riding up and down on the escalators at the local shopping centre. Staff at Jaden’s school were able to supplement this information with the fact that he is able to swim weekly but that issues with staff ratios meant he had been unable to leave school to visit the shopping centre for 6 months.

We also found that many of the activities David enjoys accessing in the home or the community are enabled by his Direct Payment Support Worker. We were able to observe directly David’s communication of enjoyment in these activities. However, David’s family were able to add the information that at the time the Local Authority were planning to cut David’s Direct Payment, which would make many of these activities inaccessible to David.

These findings have significant implications for policy and practice and would not have been identified without the supplementary information made available by families and staff who know young people well.

Equally, the concerns about staff ratios or Direct Payment were better understood in terms of their impact on Jaden and David through having directly sought their views about what they enjoy.

In both cases we fed back our findings to the relevant Local Authorities and Transforming Care Teams.

Conclusions/Recommendations

This project was a small-scale piece of work, combining the expertise of the Tizard Centre and the Challenging Behaviour Foundation to seek the views and wishes of young people with severe learning disabilities. We found that the mixed methods approach allowed us to gather a huge amount of information about each young person, what they enjoy and about their support. We also found that all families appreciated the efforts made, even where particular activities did not work out. Preparation was key to successful visits, in particular when the researcher was new to the young person.

We found that we were able to gain information from and with all the young people about what they enjoyed and that families were able to supplement this information with important context.

We would like to see all commissioners and providers of support for children and young people with severe learning disabilities taking active steps to seek their views directly. We would also like to see all consultation processes relevant to disabled children and young people adapted to include a strand which is accessible to young people with a severe learning disability.

We hope this small scale, unfunded piece of work will be a first step towards developing new and better ways to seek the views, wishes and perspectives of people with a severe learning disability (of all ages) and that such engagement becomes par for the course, rather than an unusual and innovative project.

For more information see www.challengingbehaviour.org.uk/driving-change/seldom-heard

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