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Division of
Clinical Psychology



Good practice examples from ‘Hearing the Voice’ of children and young people with moderate, severe or multiple and profound learning disabilities

Stream 3 of the wider project: Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

July 2021

We were interested in hearing about helpful ways to listen to the ‘voice’ of children and young people with moderate, severe or profound and multiple learning disabilities. When we say ‘voice’ we mean communication, in whichever form works best for the child or young person. We asked people to write a summary of what they are doing and send it to us.

This document contains summaries of what people did, what was helpful and what were the barriers. The summaries contain lots of ideas that can be applied to working with children and young people of different ages with a range of complex needs across the levels from own life, through service development, training and research and community and cultural change.

Find more information here:

<https://www.corc.uk.net/outcome-experience-measures/feedback-and-outcome-measures-for-children-and-young-people-with-learning-disabilities/>

Good practice examples from ‘Hearing the Voice’

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

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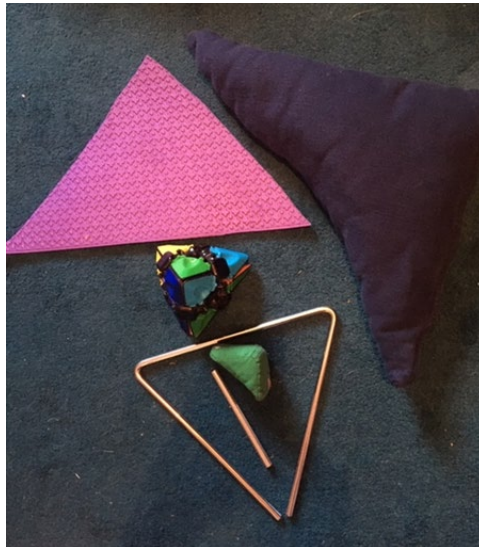
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1. Advocacy for children and young people with disabilities and emotional needs – reflections on keeping going during the Covid 19 pandemic

Maxine Cole, Triangle: Reflections and advice from a young person's advocate about supporting young people during the Covid 19 pandemic

WHAT I DO

I regularly communicate with children and young people about their wishes and feelings . I use objects of references to show that I work for Triangle, not for police or social services.



I ensure as much as possible that we have the same structure each sessions with choices, for example:

- Intro, recap and check actions from last time
- What's relevant today and adapt to what young person needs
- What's good?, what's bad? , thumbs up/down, smiley faces, what would you change? If you were boss/in charge (say name of person in charge, government- depending on level, of understanding-)
- Know area of likes eg food, what would choose, tailor to likes/dislikes eg another person noisy at night- scaffold for initial bit, then come up with ideas, e.g. if could go anywhere/favourite activity - if you could wish for anything?
- Recap actions today
- How was today?
- Want to meet again?

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Since lockdown I have been meeting with young people remotely mainly through Facetime.

I have been reassuring them what COVID is -not just them- everyone, as they may be so isolated, they don't realise. Shares that as Max 'I can't do this', '... go there', 'haven't seen own family, eg neice's birthday', person's 'mum and dad can't go out'. Chat- at the level they can cope with. Check out with staff what impact is and who to, by reading book and using symbols. I always offer time to think about COVID and acknowledge impact eg staff wearing masks, not seeing family etc.

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WHAT HELPS

1. Knowing young people over a period of time
2. Young people knowing FaceTime from contact with families before
3. Meet the same time and day each week
4. Objects of reference and symbols
5. Carers that know young people well
6. Calm bags /Fiddly toys; safe and not noisy.
7. Activities to do, always art equipment
8. Reassuring that I don't know what's important to them, as everyone is different.
9. Reflecting back what I have observed and heard.

WHAT ARE THE BARRIERS?

1. Technical issues
2. My contact not being written in diary
3. Behaviours that challenge
4. Staff views versus young person's views

RESOURCES USED AND/OR PUBLICATIONS TO SIGNPOST /REFERENCE

Activities to do, always art equipment

Free books from Timpsons with colourful pictures: A Guide to Attachment; How to Create a Positive Future; Looking After Looked After Children useful for issue specific consultations;

<https://www.timpson-group.co.uk/alex-timpson-trust/free-books/>

<https://www.timpson.co.uk/timpson-books/how-to-series.html>

Calm bags /Fiddly toys Calm bags – kits from Triangle or make your own Resources | Triangle

<https://triangle.org.uk/resource-categories/kits>

covid info; https://nosycrow.com/wp-content/uploads/2020/04/Coronavirus_INS.pdf

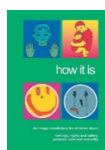
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Easy read – A guide to your COVID-19 vaccination for people with a learning disability and their carers (publishing.service.gov.uk)

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/961301/PHE_11843_Covid-19_vaccination_Easy_Read_guide.pdf

Creating/tailoring books for individuals- personal story in narrative to help cope with eg missing people, can't see because of COVID, or is in prison. Using photos and their photos and their drawings – makes permanent (often forget ideas with any stress) and sharing with others experiences



How it is. image vocabulary

<https://www.triangle.org.uk/files/2017-05/how-it-is-2002-an-image-vocabulary-for-children.pdf>

Objects of reference Objects of Reference <http://www.totalcommunication.org.uk/objects-of-reference.html>

Two Way Street Intro video https://triangle.org.uk/resource-categories/downloads?page_resource-category_downloads=2

2. Advocacy for children and young people with disabilities and emotional needs – young people's advice about hearing their voice

Maxine Cole, Triangle

WHAT I DO

I met with 3 groups of young people in their lounge at their residential home in Sussex. The young people communicated in a mix of speech, sign and writing. I spoke with 6 young girls and 6 young boys all aged between 13 and 16 years old. I told them I had been asked to help with a project called 'Hearing the voice of children and young people', that I would like to ask them 6 questions, and they would get a voucher for their help and time. I told them I would write their answers into a report and it will not say their names.

CONSULTATION RESPONSES

I told and showed the group there are no right or wrong answers. All young people showed me thumbs up.

1. 'HOW DO GROWN-UPS LISTEN TO YOU?'

- I asked 'Listen well?', 2 young people agreed.
- One young person signed 'meeting' 'talk about flowers outside' – they had asked to plant flowers in the garden and had.
- One young person communicated, 'staff had not worn masks when I asked them to'.
- 2 young people said 'in keywork'.
- One young person signed 'signing'

Other comments included:

- 'On Monday evenings I attend the students meeting'.
- 'Looking at us'
- 'Answer me and wait for me to answer and then they reply'
- 'No right or wrong answers'

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2. 'WHAT HELPS GROWN-UPS LISTEN TO YOU?'

- 'I don't know'
 - 'When you ask for help, they listen to you and then do it'
 - 'I asked to help with laundry and they listened and I did'
 - 'Having visuals', 'being able to sign', 'using voices', 'writing' and 'ipads'
 - Adults suggested:
 - 'They ask you questions and you chose which bit to answer', 2 young people agreed.
 - 'Good meetings', 2 young people nodded
- 'Repeating sentences and staff start sentence and young people finish it'

3. WHAT DO GROWN-UPS DO THAT'S GOOD? (WHEN THEY LISTEN)

- 'They give me time to talk'
- 'Help us if we have asked'

The group thought this was the same question as above

4. WHAT DO GROWN-UPS DO THAT'S BAD? (WHEN THEY LISTEN)

- 'I don't know'
- 'Wearing masks as I can't hear them or its delayed', 3 young people agreed.
- 'If someone doesn't listen to me, I feel sad'.

'Nothing', most of the group agreed with this.

5. GIVE PEOPLE ONE TOP TIP TO LISTEN BETTER?

- 'Give me options' eg this or that or something else.
- 'Use my name'
- 'A quiet room'
- 'One to one'
- 'Use symbols, signs and words'
- 'Use feeling cards'
- 'Don't wear a mask'
- 'Listen properly and hear what I say', two young people agreed with this.
- 'Please help me sometimes when I ask'

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- 'Signing', 2 young people agreed with this
- 'Choices'
- 'Make eye contact'
- 'Be helpful'
- 'Talk to me'

6. HOW HAS COVID BEEN FOR YOU?

- 'Quite stressful as I have not seen my family yet.'
- 'I had it so I was worried but I had no symptoms.'
- 'It was OK'
- 'Bit hard because I have not seen my nanny who lives abroad.'
- 'All rubbish', 2 young people agreed
- 'A little bit rubbish'
- 'Schools been shut so good to have time off school'
- 'Can't play with friends'
- 'I don't understand the different bubbles at school where I can't play with my friend but I live with him here.'
- A young person signed 'sad', thumbs down, 2 young people agreed .
- 'I am tired of Covid'
- 'Covid is not good it's bad'

3. Working with a group of young people with PMLD and complex communication needs to create a conference presentation about 'top tips' for participation

Team Epic Participation Group, Sam Greedy, Andy James, Charlotte Fry, Gareth Excell and Team Epic

PROJECT SUMMARY

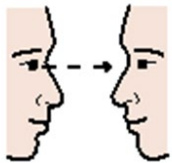
- We had run other participation groups in SEN schools, looking to hear the voices of children and young people with LD. We wanted to facilitate a group for young people with PMLD and complex communication needs.
- We ran sessions to explore what participation means, to help young people to recognise the power of their voice.
- We offered multiple sensory sessions, where students were able to say what they liked and didn't like.
- We looked at the school environment – what they liked and didn't like and what they wanted to change or improve and this information was taken to the school council.
- The group fed back their thoughts, and everyone in the group listened to each other.
- We created a team banner – everyone participated by contributing a square they decorated, with the things that made them happy, creating a collective representation of Team Epic.
- We created our 'top tips for participation' and presented this at an 'Experts by Experience' conference hosted by the British Psychological Society.




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TEAM EPIC TOP TIPS FOR PARTICIPATION



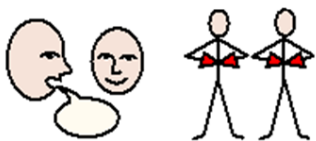
Make eye contact



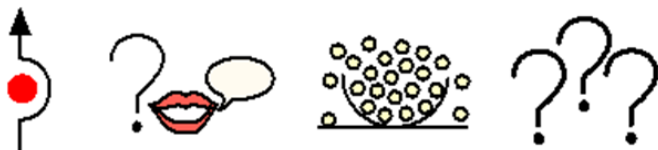
Avoid using complicated language




Give us time to answer



Talk to us



Avoid asking too many questions



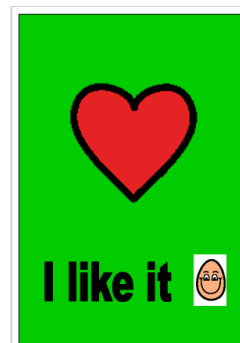
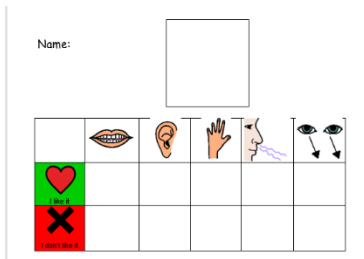
Use visuals or objects

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WHAT HELPED?

- Gareth (Class Teacher) was very passionate about participation and was motivated to support this
- The students were actively involved in the school council, so felt able to share their views
- Sessions were at the same time, to ensure the same structure and routine
- Visuals and photographs to support our verbal communication



WHAT WERE THE BARRIERS?

- Students used communication aids, which we were unfamiliar with initially
- Range of communication needs (e.g. a student who was deaf, who was reluctant to sign and did not have a communication aid set up at the time of the sessions)
- Very reliant on staff knowing the young people and how they communicated

Resources used and/or publications/websites to signpost /reference: Team Epic, James, A. & Greedy, S. Presentation 'We talk, you listen' <https://www.bps.org.uk/member-microsites/dcp-faculty-people-intellectual-disabilities/events>

4. Mental health and emotional literacy in children and young people with special educational needs and disabilities: self-report and performance measures versus teachers' ratings

Emma Jackson and Biza Stenfert Kroese, Investigating the relationship between emotional literacy and mental health using an adapted self-report measure

BACKGROUND

The present study investigates the relationship between emotional literacy (EL) and mental health in children with Special Educational Needs and Disabilities (SEND) and whether EL moderates the strength of the relationship between self and teachers' reports of mental health. A further aim was to explore the utility of an adapted self-report measure of mental health, as existing screening methods solely rely on data from parents and/or teachers.

METHODS

A series of tasks were used to assess children's EL. The teacher version of the Nisonger Child Behaviour Rating Form and an adapted self-report measure, Me and My School, were used to measure children's mental health and behaviour. Correlations were applied to identify the relationship between self-report and teacher scores of mental health, along with a moderation analysis of EL.

FINDINGS

A moderate significant positive correlation was found between teacher and child reported scores of mental health and behaviour, with many subscale scores correlating in the predicted direction, suggesting criterion validity of the adapted Me and My School measure. Children's EL did not moderate the strength of the relationship between self and teacher reported scores.

CONCLUSIONS

The ceiling effect observed for EL tasks may explain the lack of moderation effect between self and teacher-reported scores of mental health and behaviour. Findings have implications for how the mental health of children with SEND can be screened in school settings and may lead to further validation of self-report measures of mental health for children with SEND.

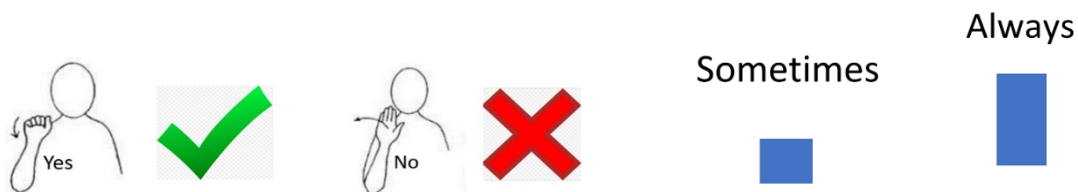
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WHAT HELPED?

- Ensuring measures were simplified, adapted and that accessible language was used, with an example question to help children understand the response scale and further standardised prompts if required. Response scales and questions were asked and explained verbally alongside visual aids.

Examples of the adapted response scale for the mental health and behaviour screening tool, Me & My School (Me & My Feelings) (Deighton et al., 2012):



- Liaising with teachers before speaking to the children ensured that any additional needs or requirements were planned for prior to administering the tasks and questionnaire.
- The study taking place in a room which children were comfortable in, as well making children aware of the option for breaks if needed and that a familiar member of staff could be present if they wished to put them at ease.

WHAT WERE THE BARRIERS?

- Utilising emotional literacy tasks which were accessible to children with a range of learning difficulties and disabilities, but also challenging enough to differentiate those with lower emotional literacy skills. Tasks appeared accessible and acceptable to all children who took part, but a ceiling effect was observed for many of the children, therefore tasks were unable to differentiate between those children with higher and lower ability levels regarding their emotional literacy skills.

Trying to adapt tasks to include children who were not able to communicate with single word responses. Therefore, these children unfortunately had to be excluded from the study.

CLINICAL IMPLICATIONS

Clinical implications of the present study are that findings may influence how the mental health of children and young people with SEND is screened in schools, and potentially within clinical practice. Improved mental health screening of this population, which incorporates self-report measurement may lead to earlier interventions that are more tailored to children's needs. A further implication may be the use of the SEND version of Me and My School as an outcome measure in the evaluation of mental health promotion and emotional literacy intervention programmes, within clinical and SEND educational settings. Valid and reliable mental health screening for children with SEND should be a priority and of an equal standard to children without SEND; even more so because these children are four and a half times more likely to develop mental health difficulties (Emerson & Hatton, 2008). This research hopes to influence how the mental health of children with SEND is screened and inspire researchers to establish further validation of the Me and My School measure for children with SEND.

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RESOURCES USED AND/OR PUBLICATIONS/WEBSITES TO SIGNPOST /REFERENCE:

Aman, M., Tassé, M., Rojahn, J. and Hammer, D. (1996). The Nisonger CBRF: A child behaviour rating form for children with developmental disabilities. *Research in Developmental Disabilities*, 17 (1), 41-57.

Deighton et al. (2013). Me and My Feelings School measure. Wellbeing Measurement Framework for Primary Schools. EBP/Anna Freud Centre.

Tassé, M., & Aman, M. (1996) Nisonger Child Behavior Rating Form (NCBRF) Parent and Teacher versions. Nisonger Child Behavior Rating Form - Nisonger Center (osu.edu)

5. The views of some adolescent, non-verbal young people on a process to improve intimate care practice in a special school

Jude Liberman, Hearing the views of young people about a pathway to support intimate care practice

INTRODUCTION

I completed some research as part of a thesis towards a Professional Doctorate in Educational Psychology (DEdPsy) with University College London (UCL). The overall thesis is titled:

Transition to adulthood for young people who require intimate care support in schools: Can an Intimate Care Pathway help?

One element of this study was an exploration of the views of young people relating to intimate care practice.

CONTEXT

My study was set in a special school context from 2016-2019. This school caters for children and young people with physical disabilities, severe learning difficulties and Profound and Multiple Learning Difficulties. The approximately 70 students in this school also present with a range of other difficulties including complex health needs and sensory impairments. Very few have any functional speech and many use communication aids, including some using eye gaze technology where the child looks at cells on the screen and the direction of their eye pointing is detected. I describe these young people as experiencing complex learning difficulties and disabilities (CLDD).

LITERATURE REVIEW SUMMARY

As part of this project, I investigated if the views of children and young people with this level of need are represented at all in the literature. I searched for young people's views on the broader area of transitioning to adulthood.

YOUNG PEOPLES' PERSPECTIVES OF THE TRANSITION TO ADULTHOOD

In 2016 when the literature search was first completed, only one piece of literature (Stewart et al., 2002) was found which gave the views of young people from a somewhat comparable population to those with CLDD. However, the suggestion from the findings is that these young people were more able to

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communicate their views than the young people I was planning to interview. Stewart et al. (2002) completed a qualitative study in Canada, in order to ‘explore the experience, perspectives and needs of youth with physical disabilities in transition to adulthood’ (p.3). Semi-structured interviews were used with findings analysed using an editing style described as a ‘continuous evolution’ coding method with support from a computer programme to sort the data repeated until saturation. The study purports to represent young people’s views but it is interesting that the participants are 21 young people, 12 parents (some of whom were interviewed individually) and 1 service provider.

It is difficult for the reader to distinguish the ‘voice’ of the young people participants from the adults interviewed and perhaps different sections of the study for different participant groups could have been useful. It is also difficult to understand how the views of the non-verbal or communication aid user participants have been elicited and included. Despite these questions around methodology, the richness of the findings cannot be discounted. For example, Stewart et al. (2002) concluded that the transition to adulthood for this population presents with the greatest challenges:

As they grew older, youth with congenital disabilities started to look to the future in the adult world and found that their journey had taken them to the edge of a cliff. Across the gap there existed an adult world which was unfamiliar with persons with difficulties ... and this made the gap between the two worlds even greater. This gap appeared to be greatest for young people who were dependent for daily care on their parents. (Stewart et al., 2002, p.16)

The study established some recommendations for service planning and delivery in Canada, which cannot be assumed to be directly relevant in the UK. The study does recommend that further research explores the experiences of transition to adulthood for young people with:

‘(...) different types of disabilities and in different communities’ in order to ‘facilitate communities in coming together to influence planning and decisions about transition services at different levels’ (p.19).

This resonated with some aims of my study and certainly with the premise of better understanding the experience of transition from multiple perspectives. When the literature search was repeated in February 2018, another paper was found that claims to have elicited the views of ‘young people with learning disabilities and their families’ (Pallisera et al., 2016, p.391) in Spain and with a different population of young people. However, using an interesting mixed qualitative methodology with interviews and focus groups, they captured a sense of the voice of the 8 young people who participated.

Findings are not generalizable beyond the context or location of this study, however the premise is directly relevant. In order to complete their in-depth exploration of experiences around transition to adulthood, the authors explain that:

(...) we need to know the views held by young people with disabilities and their families...Few studies have taken their voices into account when addressing this transition (p.392).

Amongst more specific recommendations, Pallisera et al. (2016) recommend that young people and their families receive timely information about the changes that they all might face over this transition to adulthood.

They conclude with discussion about the rights of young people to be at the centre of their transition planning and making of choices around them.

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AIMS AND SAMPLE

My qualitative study investigated the perceptions of parent/carers and school staff linked to one special school, supporting young people with CLDD with intimate care needs as they transition through adolescence to adulthood, with the aim of better understanding these experiences. The research also investigated views about Intimate Care Pathways (ICPs), a process designed to support intimate care practice, in order to explore and identify key principles in intimate care practice. Four non-verbal young people participated in this aspect of the research.

METHOD

The young people were interviewed individually according to an interview schedule. The interview followed an ethical practice design as it was difficult to be confident in consensual participation without this.

The four young people were asked using a thorough, iterative ‘consent process’ (see Table 2) to indicate that they understood what would be happening and what would happen to the information that they gave. They were asked about their experience of intimate care and intimate care pathways using a carefully constructed, significantly differentiated, interview process that was interwoven with the consent process.

A significant level of modification was required to interview these non-verbal young people and it was decided that a focus on their views about the intimate care pathway process rather than less tangible concepts such as their feelings about their own adolescence, was deemed the most appropriate focus of the interviews. Learning and potential emotional wellbeing needs were considered in this design.

See Table 1 for further explanation.

Table 1: Summary of research design modifications made to support young people participants

Potential Area of need	Design modification
Level of understanding	<p>The focus was on the Intimate Care Pathways rather than more complex issues around adolescence or needing intimate care. The Intimate Care Pathways was deemed to offer something tangible to evaluate.</p> <p>Simple positive statements were made. The young person was asked a repeated question ‘Do you agree?’</p> <p>Objects were used as prompts e.g. change pads or aprons</p> <p>Symbols were used that were familiar to the young person</p>
Communication	<p>The young person had a communication aid and/or low tech communication support available</p>

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An adult supported the young person in using their communication aids and/or was familiar at reading their non-verbal communication e.g. eye flicks and could share this with the researcher.

Emotional
Wellbeing

An adult who knew the young person well accompanied them through the interview. The consent process was repeated throughout the interview, giving the option to withdraw at any point.

Table 2: Interview schedule and iterative consent process

	Verbally presented question by interviewer	Buttons on communication aid	Description of process for this question
	<p>Introduction:</p> <p>We are going to talk about your Intimate Care Plan.</p> <p>That is what happens when you go to the bathroom</p>	Familiar visuals relating to bathroom use to support understanding.	<p>Interviewer to show paper copy of intimate care plan template with their name on it but no other information.</p> <p>Show visuals and objects relating to the bathroom e.g. apron and gloves, a packet of wipes etc.</p>
1	Do you know what your intimate care plan is?	<p>Yes</p> <p>No</p> <p>I don't know</p>	<p>If 'No' or 'I don't know':</p> <p>Interviewer to repeat process of showing paper copy of intimate care plan template with their name on it.</p> <p>Show visuals or objects of reference relating to the bathroom e.g. apron and gloves, a packet of wipes etc.</p> <p><i>If response continues to be 'No' or 'I don't know' terminate interview here</i></p>
2	Can we talk about intimate care plans?	<p>Yes</p> <p>No</p> <p>I don't know</p>	<p>Show intimate care plan template with their name on it but not populated.</p> <p>Show visuals or objects of reference relating to the bathroom e.g. apron and gloves, a packet of wipes etc.</p> <p><i>If response continues to be 'No' or 'I don't know' terminate interview here</i></p>

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	Verbally presented question by interviewer	Buttons on communication aid	Description of process for this question
	I am going to say something about your intimate care plan.		
3	My intimate care plan means that people understand how to help me Can you tell me if this is 'True', 'not true' or 'you don't know'	Include buttons with 'true', 'not true' or 'I don't know' Or if more appropriate 'Yes', 'No' and 'I don't know'	Press each button on the communication aid and check for understanding Show document with their name on it but no other information)
4	I worry that people won't do things right Can you tell me if this is 'True', 'not true' or 'you don't know'	Include buttons with 'true', 'not true' or 'I don't know' Or if more appropriate 'Yes', 'No' and 'I don't know'	Then show visual or object to help them understanding of the question as appropriate.
5	My intimate care plan means I can do more for myself OR My intimate care plan means I can be more independent Can you tell me if this is 'True', 'not true' or 'you don't know'	Include buttons with 'true', 'not true' or 'I don't know' Or if more appropriate 'Yes', 'No' and 'I don't know'	Return to any questions where it was not felt that young person understood and ask one more time. Accept any verbal or nonverbal responses that clearly indicate an answer to the question
6	My intimate care plan means I feel more involved Can you tell me if this is 'True', 'not true' or 'you don't know'	Include buttons with 'true', 'not true' or 'I don't know' Or if more appropriate 'Yes', 'No' and 'I don't know'	
7	I worry that people won't do things right Can you tell me if this is 'True', 'not true' or 'you don't know'	Include buttons with 'true', 'not true' or 'I don't know' Or if more appropriate 'Yes', 'No' and 'I don't know'	
8	My intimate care plan helps me feel safe? Can you tell me if this is 'True', 'not true' or 'you don't know'	Include buttons with 'true', 'not true' or 'I don't know' Or if more appropriate 'Yes', 'No' and 'I don't know'	

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	Verbally presented question by interviewer	Buttons on communication aid	Description of process for this question
9	<p>Would you like to take the Intimate care plan with you when you leave school?</p> <p>Can you tell me if this is 'True', 'not true' or 'you don't know'</p>	<p>Include buttons with 'true', 'not true' or 'I don't know'</p> <p>Or if more appropriate 'Yes', 'No' and 'I don't know'</p>	
10	<p>Who would you like to see your intimate care plan? <i>(from a given selection)</i></p>	<p>Yes</p> <p>No</p> <p>I don't know</p>	<p>Hold up intimate care plan proforma with their name on but no other details.</p> <p>Demonstrate an action of giving this to another adult.</p> <p>Show photos of parent/school staff/respice staff/nurse and any key adults. Ask young person pick yes/no or I don't know as you mime giving the document to each.</p>
11	<p>Which of these is important? I am going to show you all of them. Can you then pick the really important ones for you?</p>	<p>Include buttons that read out the following statements:</p> <ul style="list-style-type: none"> – I want to feel safe – I need to know what is going to happen in the bathroom – I want to take this Intimate care plan with me to other places – I want everyone to know what I want – I want to do more for myself – I want to be independent – I want to be involved – I don't know – I don't care <p>Give options:</p> <p>'It is important', 'it is a bit important', 'it is not important' or 'I don't know'</p>	<p>Click on each button for the student. Then ask them to select from 'It is important', 'it is a bit important', 'it is not important' or 'I don't know'. The visuals should link to the questions that have been used throughout the questionnaire.</p>

Good practice examples from ‘Hearing the Voice’

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

PARTICIPANTS

I asked school staff if students could consistently respond using ‘yes’/‘no’ responses as a requirement for them to participate. A small group of four young people aged 18 were deemed by school staff to be able to understand sufficiently to be able to give reliable responses both in terms of their consent to participate and in their answers to questions. This therefore represents an opportunity sample.

PLANNED INTERVIEW QUESTIONS AND FORMAT FOR YOUNG PEOPLE

As part of the school’s review of the Intimate Care Plan process, prior to my consideration of this research project, a student was interviewed on camera by school staff and has given consent for this video to be shared for training purposes. In response to verbally presented questions, he was guided to buttons (electronic) on the touch screen of his communication aid, which he then pressed to generate a verbal response. These responses had been pre-recorded by staff with the young person’s agreement. The young person responded with the word ‘Yeah’ and nodding his head and smiling as the interviewer checked that the response ‘spoken’ by the communication aid was in line with his views.

I was not involved in the setting up or facilitation of this interview but I have used the information from this video footage to inform how I have developed a process of gaining the views of the group of young people that is most likely to capture their views in an authentic and age-appropriate way but taking into consideration their significant learning and communication difficulties.

PERCEPTIONS OF YOUNG PEOPLE

The research method was carefully planned to increase the likelihood that the responses given by the young people would be authentic despite the barriers to communication that they face. These findings cannot be generalised or reported collectively. They give a window of insight into the experiences of four individuals. One chose to leave the interview and return to the class.

YOUNG PEOPLE INTERVIEW RESPONSES

	Verbally presented question by interviewer	Communication method available to young person	Response given
	Introduction: We are going to talk about your Intimate Care Plan.	Familiar visuals relating to bathroom use to support understanding.	Interviewer to show paper copy of intimate care plan template with their name on it but no other information.

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

	Verbally presented question by interviewer	Communication method available to young person	Response given
	That is what happens when you go to the bathroom		Show visuals and objects relating to the bathroom e.g. apron and gloves, a packet of wipes etc
1	How do you feel about going to the bathroom?		
	T	Picture symbols for embarrassed/anxious/sad/happy	'Safe' symbol selected
	A	Lifts eyes for yes. Shown pictures in turn and asked for response	Staff interpreted that she lifted her eyes for 'yes' in response by showing the 'anxious' picture and slightly for the 'safe' picture
	S	Uses an eye gaze communication aid and also raises eyes for yes	In response to being shown the pictures of feelings, responded 'No' on his tellus for 'sad' 'anxious' and 'embarrassed' and 'yes' for safe
	J	Uses an eye gaze communication aid and also raises eyes for yes	Selected 'class', 'class' on Voca then responded when question repeated, using Voca to select 'annoyed' and 'angry'

	Verbally presented question by interviewer	Buttons/objects/symbols available	Response given	Comment
2	My intimate care plan means that people understand how to help me			
	T	Verbal response	Yes	
	A	Flicks or raises eyes for 'yes'	Yes	

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

	Verbally presented question by interviewer	Buttons/objects/symbols available	Response given	Comment
	S	Uses an eye gaze communication aid and also raises eyes for yes	No	
	J	Uses an eye gaze communication aid and also raises eyes for yes	Yes	
3	I worry that people won't do things right			
	T	Verbal response	Yes	
	A	Flicks or raises eyes for 'yes'	Yes	
	S	Uses an eye gaze communication aid and also raises eyes for yes	No	
	J	Uses an eye gaze communication aid and also raises eyes for yes	'class', 'class'. 'class'	It was decided that the interview would be terminated as J wanted to return to class
4	My intimate care plan means I can do more for myself OR My intimate care plan means I can be more independent			
	T	Verbal response	Yes.	When asked if he helps with his trousers he said 'No'. Asked if he washes his hands he replied 'Yes'
	A	Flicks or raises eyes for 'yes'	Head dropped for 'No'	

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

	Verbally presented question by interviewer	Buttons/objects/symbols available	Response given	Comment
	S	Uses an eye gaze communication aid and also raises eyes for yes	"No" using Voca	
	J	Uses an eye gaze communication aid and also raises eyes for yes	_____	
5	My intimate care plan means I feel more involved		Include buttons with 'true', 'not true' or 'I don't know' Or if more appropriate 'Yes', 'No' and 'I don't know'	
	T	Verbal response or switches pressed on Voca	Yes	
	A	Flicks or raises eyes for 'yes'	Yes with eyes flicked up	
	S	Uses an eye gaze communication aid and also raises eyes for yes	"No" using Voca	
	J	Uses an eye gaze communication aid and also raises eyes for yes	_____	
6	I worry that people won't do things right			
	T	Verbal response or switches pressed on Voca	'Bad' verbally and using Voca	Teacher said so 'It would be bad if people didn't do things right?'

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

	Verbally presented question by interviewer	Buttons/objects/symbols available	Response given	Comment
				and T replied 'Yes'
	A	Flicks or raises eyes for 'yes'	'Yes'	Response not clear to me but staff believe this was the response
	S	Uses an eye gaze communication aid and also raises eyes for yes	"No" using Voca	
	J	Uses an eye gaze communication aid and also raises eyes for yes	_____	
7	My intimate care plan helps me feel safe?			
	T	Verbal response or switches pressed on Voca		
	A	Flicks or raises eyes for 'yes'	'No' indicated with head down	
	S	Uses an eye gaze communication aid and also raises eyes for yes	"No" using Voca	
	J	Uses an eye gaze communication aid and also raises eyes for yes	_____	
8	Would you like to take the Intimate care plan with you when you leave school	Include buttons with 'true', 'not true' or 'I don't know' Or if more appropriate		

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

	Verbally presented question by interviewer	Buttons/objects/symbols available	Response given	Comment
		'Yes', 'No' and 'I don't know'		
	T	Verbal response or switches pressed on Voca	'Good' using switch	
	A	Flicks or raises eyes for 'yes'	'Yes' flicking her eyes upwards	
	S	Uses an eye gaze communication aid and also raises eyes for yes	Yes	
	J	Uses an eye gaze communication aid and also raises eyes for yes	_____	
9	How do you feel about having an Intimate Care Plan.	Include buttons that read out the following statements for the young people to choose from :e.g. Safe, embarrassed, sad, happy, excited,....		
	T	Verbal response or switches pressed on Voca	'Good' using switch and chose 'happy' picture symbol when offered a selection	
	A	Flicks or raises eyes for 'yes'	Shown picture symbols. In response to 'anxious' replied 'yes', safe 'no' and happy 'no' using eye flicks.	
	S	Uses an eye gaze communication aid and also raises eyes for yes	Chose 'safe' from the picture symbols. Asked if he feels embarrassed sometimes he	

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

	Verbally presented question by interviewer	Buttons/objects/symbols available	Response given	Comment
			selected 'Yes' using his eye gaze Voca	
	J	Uses an eye gaze communication aid and also raises eyes for yes		

SUMMARY OF REPOSSES

	Verbally presented question by interviewer	Yes	No	Other
1	How do you feel about going to the bathroom?			Anxious; Safe x3; Annoyed Angry
2	My intimate care plan means that people understand how to help me	3	1	
3	I worry that people won't do things right	2	1	'Class' *
4	My intimate care plan means I can do more for myself OR My intimate care plan means I can be more independent	1	2	
5	My intimate care plan means I feel more involved	2	1	
6	I worry that people won't do things right	2	1	
7	My intimate care plan helps me feel safe	0	2	
8	Would you like to take the Intimate care plan with you when you leave school	2	0	Good
9	How do you feel about having an Intimate Care Plan?			Good; Happy Anxious; Safe Embarrassed

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

WHAT HELPED?

There were a range of enabling factors that supported me in being able to seek the views of these young people:

- Supportive school staff who knew the young people well in order to :
 - Pre-assess their capacity to participate in the research
 - Support during the interview process

- With very familiar staff, I had noticed a tendency for staff to speak for these children/young people, reading their non-verbal communication at times and at others predicted or guessing their views/perspective. I was prepared to simplify and modify my questions as much as necessary so that the young person could respond directly to me without the need for that adult interpretation. In this way I felt that these views were more authentic.

- I wanted ideally to gain the perspectives of young people on some of the more complex questions that I used with parent/carers and school staff. However, many of these questions would have required a capacity to describe an aspiration for the future or a reflection about the past. Part of the modification of this process was to consider the capacity of these young people to reflect in that way on the past and future. I decided, instead to only ask for views relating to the most tangible aspect of the project which was the Intimate Care Pathway. To these young people this is a document that helps guide adults in their intimate care and they had participated to some extent in constructing it.

- Another consideration which helped me feel like I was ensuring informed consent was being given by the young people was the iterative consent process I describe. This, felt appropriate to the situation and when one young person did choose to leave half way through the process, I felt reassured that this he had be able to communicate this as part of this consent process.

WHAT WERE THE BARRIERS?

- As I determined that I could only reliably ask questions about the concrete process – the Intimate Care Pathway, I was unable to establish insight into the more complex feelings and experiences linked to intimate care and also growing up as a young person who needs intimate care support. I was also unable to pursue ideas to understand 'why' they might like or not like an 'intimate care pathway'. I was limited in what I could ask and hence what I could discover.

6. Working with young people to create ‘ten top tips’ to promote a sense of ‘belonging’ to their school

Tara Midgen, Theodora Theodoratou, Kirsty Newbury & Matthew Leonard, *Your opinion matters - ‘School for Everyone’: An exploration of children and young people’s perceptions of belonging*

WHAT WE DID

Following a review of provision, Wandsworth council recognised the need to strengthen its strategy for including children with Special Educational Needs and Disabilities (SEND) in their local mainstream provision. As part of this strategy and the need to involve children with SEND in decision-making, the SCPS (Schools and Community Psychology Service) agreed to explore children and young people’s understanding and thoughts regarding what helps them feel they belong in their schools, since sense of belonging has received strong support as a central characteristic of inclusion (Billingsley et al., 1996; Forest & Lusthaus, 1989; Frederickson et al., 2007). Wandsworth SCPS explored three specific questions in relation to children’s belonging. Firstly, did children within the borough feel a sense of belonging in their schools? Secondly, what helped children feel that they belong? Finally, what else did children and young people think would improve their sense of school belonging within the Local Authority (LA)? In order to answer these, a two phase, mixed-methods approach was adopted. Young people’s sense of belonging was explored using the Belonging Scale (Frederickson et al., 2007) and the School Connectedness Scale (Resnick et al., 1997), alongside individual or group reflection sessions. In the first phase, children were asked about their understanding of inclusion and belonging, and what they felt schools were doing to support them. Focus groups of up to eight children and young people (CYP) were held in school settings. Children in nursery and Key Stage 1 attended a single session focus group, whilst those in Key Stage 2 and above attended two focus groups, held in consecutive weeks. Children and young people’s understanding of belonging and inclusion was explored through group discussions.

Where it was felt that CYP did not have a clear understanding of the terms, this was explored further using differentiated games and stories and assessed with related questions. The focus groups then explored sense of belonging using further group discussions, activities, and work stations where children could write or draw their answers to questions focusing on inclusion and belonging in school.

The second phase took the themes identified in the first phase and explored these further, aiming to identify and rank the most important factors of belonging to children within the LA. CYP were shown quotes (short phrases) representing sub-themes identified from phase 1 of the research and told that these were ideas which other children in the LA felt help them belong in school.

Symbols, sorting activities and open questions were used to ensure that the students had a good grasp of the Part One: Good practice initiatives Official key themes presented. CYP were then asked to identify and prioritise the three most important themes to them and explain why they were important. Opportunities for adding further factors, which CYP felt promoted inclusion and belonging, were also provided.

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Once the Phase 2 qualitative data from the young people had been categorised by sub-theme, key sub-themes began to emerge as being relatively more important (as determined by their frequency) to CYP's sense of belonging in school.

The ten most important sub-themes and quotes from the CYP were used to create the Top Ten Tips for school belonging (see below). With the support of the graphic design team a poster was created to display the young people's key ideas adopting the title 'School for Everyone: Our Ten Top Tips to help us feel we belong.'

Official



WHAT HELPED?

- A number of factors helped to facilitate this project and encourage the children's voices to be heard.
- The fact that this was a local authority priority provided a platform to promote and encourage schools' participation and enabled SCPS to protect time for delivery.
- Children's participation and engagement is also important to schools who recognise the importance of this for their own school development and are often keen to participate in such projects.
- Having a group of practitioners committed to the project from services and schools who are motivated to hearing children's voices is key.

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

- **The methods of delivery with the children and young people enabled their participation. These included:**
 - providing small group opportunities to seek views including focus groups that helped children and young people to understand key concepts from the start of the project
 - opportunities for children to record their views in a range of ways such as talking, drawing, writing etc.
 - using creative methods to facilitate this
 - adjusting tools to suit the needs of children
 - providing visual support.

WHAT WERE THE BARRIERS?

- Participants comprised a small number of children across a wide range of ages and need from each setting limiting the possibility of any generalisability.
- Whilst the majority of CYP who took part in the project reported a positive sense of belonging or connectedness in their settings, it is difficult to rule out selection effects given the method used to identify children to participate.
- Limited time for SENCoS to gain consent, competing SENCo priorities and some parents' concerns regarding their children missing learning activities, also prevented some children's participation.
- The project tasks still required certain levels of communication and understanding, and this prevented children with the most profound needs from being included in the project.
- Given the clear deadlines to complete the data collection to present the findings to council stakeholders, there was limited time during phase 2 to ensure that all CYP fully understood the concept of belonging and some of the quotes chosen by the children when identifying which factors help them the most. It is therefore hard to be definitive as to whether children's choices were linked to their understanding of what promotes belonging or were things they considered made them happy or were important to them.
- Regardless of this, children without SEND are likely to be better at seeking out and accessing these precursors to belonging for themselves. Therefore, explicit and purposeful attention should be given to providing these precursors to belonging for children with SEND.
- The data appeared to suggest that where schools were providing targeted support to help children form positive relationships, the children's sense of belonging was positive. More Educational Psychology Service team members were involved in phase 2. Despite planning meetings and efforts to standardise the process, it was not possible to ensure that the delivery of the interviews did not have an impact on the quality and quantity of responses received.

Good practice examples from ‘Hearing the Voice’

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

RESOURCES USED AND/OR PUBLICATIONS/WEBSITES TO SIGNPOST /REFERENCE:

- Cartmell, H. & Bond, C. (2015) What does belonging mean for young people who are International New Arrivals? *Educational & Child Psychology* Vol. 32 No. 2
- Frederickson, N., Simmonds, E., Evans, L. & Soulsby, C. (2007). Assessing social and affective outcomes of inclusion. *British Journal of Special Education*, 34, 105–115.
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- Resnick, M. D., P. S. Bearman, R. W. Blum, K. E. Bauman, K. M. Harris, J. Jones, J. Tabor, et al. 1997. “Protecting Adolescents from Harm: Findings from the National Longitudinal Study on Adolescent Health.” *JAMA* 278 (10): 823–832

7. Creation of an observational framework to support young people who communicate in ways other than language to contribute meaningfully to staff recruitment

Jennifer McElwee, Mared Owen, Lucy Bennett Downes and Emma Alm, An observational framework for young people's participation in interviews

PROJECT SUMMARY

We wanted to gain the views of young people who communicate in ways other than language about candidates interviewing for a post in the NHS. As part of the interview process, we asked candidates to spend some time with a child/young person who communicated in ways other than language and their parent. We used an observational interview framework to think about engagement and used this to inform decisions about who should be offered the post.

WHAT WE DID

We spoke with Nick Gore and Jill Bradshaw about creating a framework for structured observation of 'observable indicators' of a child/young person's engagement. Working together as clinicians and parents, we created a 'Framework for structured observation' and a 'Framework for candidate feedback'.

FRAMEWORK FOR STRUCTURED OBSERVATION

Part A

This section is a short discussion or 'interview' between candidate and parent before meeting the child/young person. We wanted to give the candidate a chance to ask about the child/young person and think about how best to engage them.

A. Parent interview (assessing what candidate says):

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Question	Important points for candidate to cover	Not present (0)	Partially present (1)	Fully present (2)
What would you like to know about (<i>my child</i>) before you meet?	<ul style="list-style-type: none"> • How the child communicates • What child enjoys • What makes the child happy • What child is interested in • How best to engage child 			

Additional comments:

Part B

This section is focussed on observable indicators that the young person is engaged, alongside observations about how the candidate is trying to engage the young person.

B. Time spent with (*child*) (assessing what candidate does):

(i) Is (*child*) engaged?

Indicators of (child)'s engagement

Indicator	Not present (0)	Partially present (1)	Fully present (2)
Smiling			
Eye contact			
Initiating interaction			
Following/copying the candidate's lead			
Engaged body language e.g. animated body movements			
Specific signs of (<i>child</i>)'s engagement:			
Add signs specific to child			

Good practice examples from ‘Hearing the Voice’

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Additional comments:

(ii) What does the candidate do to try to engage (child)?

Indicator	Not present (0)	Partially present (1)	Fully present (2)
Smiling			
Eye contact			
Initiating interaction e.g., using visuals/objects of reference, signing			
Following/copying the child/young person’s lead e.g. alter tone/speed of voice according to context			
Engaged body language e.g. getting on the same level as the child			

Does this vary according to need?

No (0)	Possibly (1)	Yes (2)

We really value child/young people’s and parents’ views around engagement and connectedness that are hard to capture within more formal interview processes. Part B therefore includes a section to capture more qualitative feedback.

2. Overall impression

(i) Would you as a parent want to work with this candidate?

No (0)	Possibly (1)	Yes (2)

Why?

(ii) Would (child) want to work with this candidate?

No (0)	Possibly (1)	Yes (2)

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Why?

(iii) What is your overall impression? Is this candidate appointable?

Why?

FRAMEWORK FOR CANDIDATE FEEDBACK

We wanted to hear candidate's thoughts about the observation process and also give them space to reflect on anything they noticed or would have done differently. We were also interested to see if candidates and observers' ratings of behaviour were similar.

Introduction

We would like to give you a chance to reflect on the process of being part of the child and parent interview. We understand that you will have very limited time to reflect, and are looking only for your initial reaction to being part of the process. Please take a maximum of ten minutes to complete this form and then hand in to reception.

A. Meeting the parent

What was it like to meet the parent?

B. Time spent with the young person

Did you notice these indicators of the child's engagement?

Indicator	Not present (0)	Partially present (1)	Fully present (2)
Smiling			
Eye contact			
Initiating interaction			
Following/copying the candidate's lead			
Engaged body language e.g. animated body movements			
Specific signs: Fill in signs			

Did you use these methods to engage the child?

Indicator	Not present (0)	Partially present (1)	Fully present (2)
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Good practice examples from ‘Hearing the Voice’

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Smiling			
Eye contact			
Initiating interaction e.g., use visuals/objects of reference, signing			
Following/copying the child/young person’s lead e.g. alter tone/speed of voice according to context			
Engaged body language e.g. getting on the same level as the child			

Is there anything you would like to add?

WHAT HELPED?

- It was really important to work with clinicians and parents as co-creators of this framework and documentation. This enabled us to incorporate different points of view about what we should be looking out for.
- Working with children/young people in this way gave us a completely different insight into candidates that we weren’t able to capture during the formal interview.
- Setting up the interview process so that children/young people had fifteen minutes with the candidate, followed by a break and an opportunity to go outside, meant that the children/young people stayed focussed and had fun.

WHAT WERE THE BARRIERS?

- We asked the parent and a clinician to be observers, and there was also another clinician in the room to support the child/young person. This meant that there were a lot of adults in the room when the candidate was also present. Next time, we will aim to work with observers behind a screen to reduce the number of people in the room.
- Trying to organise logistics so that the child/young person was part of the process, had a chance for regular breaks, but didn’t have to be present for too long, alongside the formal interview process. We managed to create quite a complicated timetable with candidates moving from the observational part of the interview through to the formal interview process, which worked most of the time!

8. Adaptation of an existing NHS resource pack for use with a young person living in a Residential Care Home

Hazel Sharpe, Talking about restraint

PROJECT SUMMARY

We adapted an existing NHS resource pack (My Restraint Story) for use with a young person resident in a Children’s Disabilities Residential Care Home. The Positive Behaviour Support (PBS) Team provided resources and training to care home staff who did direct work with the young person. The PBS team then took the information and incorporated it into the young person’s PBS plan and used it to inform staff development.

WHAT WE DID

The aim of this project is to try to understand what a young person feels about being restrained when they are unable to express this verbally. We have adapted the ‘Talking Mats’ process to capture a young person’s thoughts and feelings following an incident of restraint.

We’ve been meeting as a Restraint Reduction Network in Sussex. We were given a debrief document from but we have found that Talking Mats are less formal, more appropriate and familiar to the young person.

Before a debrief session, we have a pack ready with two bits of felt (we let the young person know this is where ‘like’ goes and this is where ‘don’t like’ goes), generic pictures of the house, images of feelings, picture of a body, photos of staff, photos of restraint holds demonstrated by staff and another young person. We start by chatting to the young person and then the preferences are put in the middle of the two felt mats.

The debrief process starts with ‘are you hurt now and where’ using the picture of the body – this is child-led so does not always follow the same pattern.

Typically, the young person is asked how she is feeling. The young person normally talks about how she was feeling before the incident. Then the facilitator asks ‘where did you start to feel sad?’ and young person chooses a location. Then the young person will be asked about how they feel in their body and there will be a picture of a body to prompt. Then we talk about restraints if the young person is still engaged (may need a break). The facilitator will be talking about the people involved in the restraint. The young person might show/say that a member of staff was making her feel cross.

Then the young person is shown pictures of restraint and asked about how she experiences this. It is important to manage expectations so that the young person knows that they may not like it but sometimes staff may need to do the restraint in order to keep the young person safe.

Good practice examples from ‘Hearing the Voice’

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

The people who facilitate know the young person well and are good at communicating with her. This is a multi-agency approach as we need to work closely with all people supporting the young person.



WHAT HELPED?

The young person will often use echolalic speech that does not properly represent her feelings. She does reliably pick images that help her express herself better. The more emotionally charged a topic, the more she will rely on echolalia or go off on tangents. The images help her to stay on subject. Staff who do the sessions with her describe her visibly relaxing as she shares her story.

While it is impossible to say we will not use an identified restraint again, having the conversation around why it is used is helpful to the young person. It also flags up the need to readdress this after every restraint.

WHAT WERE THE BARRIERS?

In our example the young person identified a restraint as “not liked”. It was impossible to tell her we would not use that restraint, but the conversation around why and when it is used was felt helpful. It also highlighted the need to revisit this in any further de-brief after restraint.

It took some time to create resources and find images that represent the restraint meaningfully to the young person.

Once hold was identified as “not likes” it was hard to establish with staff what the instruction in the PBS plan to “avoid” its use meant. In practice, the hold is only used when absolutely necessary. We wanted to represent the child’s voice. Including the comment may not change practice -there was a danger that staff would not use a hold that was required to keep the child safe.

9. Development of a range of tools to promote pupil voice in schools

Sarah Taylor-Whiteway and Siobhan Hickey, Promoting Pupil Voice at Paddock School for Children and Young People with severe learning difficulties

PROJECT SUMMARY

We worked in collaboration with staff at Paddock School during the development of tools to promote pupil voice and also used trainee Educational Psychologists to develop pupil voice packs as part of a wider toolkit.

WHAT WE DID

We developed 6 tools in an attempt to support all students within the school to express their views. The school were already using SCERTS® (Social Communication, Emotional Regulation and Transactional Support) to understand the communication skills of their students. We developed 6 tools that mapped onto each of the SCERTS levels with the understanding that CYP may be able to access other tools outside of their SCERTS level.

Social partner – observation schedule/blank room test

We are learning about	What interests me	How I make sense of my world	How my world makes me feel	If I want to communicate with you	How you can support me to access my world	If I am motivated to seek what I like
Eg. Time	What I am looking at	What I am using to explore the object (eg. hands, mouth, nose)	My facial expression, any sounds I am making	Attempts at engagement, eg. eye contact, gestures, sounds	Support needed and provided	What I seek and how it is sought

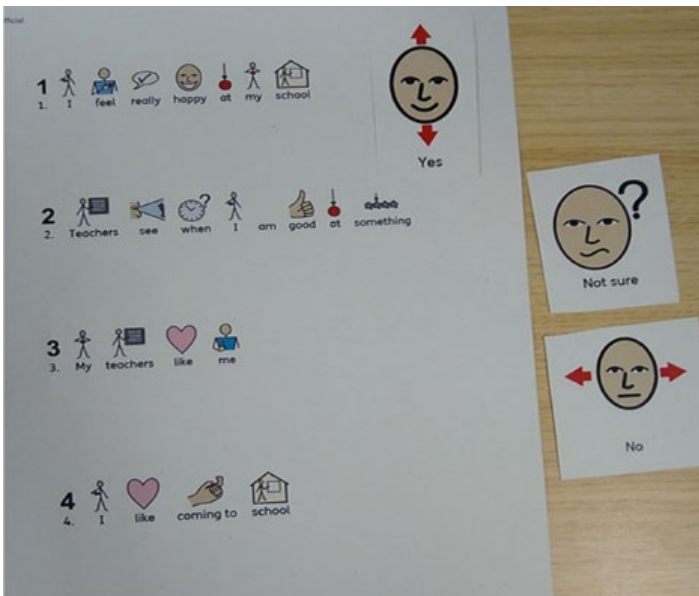
Language partner – sorting mat/Mosaic approach

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)



Conversational partner – belonging scale/interview schedule



Some of the tools were adapted from resources already available and trialled with staff in school who then suggested their own amendments to create them fit for purpose and increase even further the person-centred nature of the project.

WHAT HELPED?

- The school was willing to invest time and energy to this project – using some of our commissioned time to complete the project and encouraging all staff to attend twilight sessions after school and building it into their appraisal system.
- Using the established SCERTs model within the school to differentiate between language levels gave us a strong starting point to research and develop the tools

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

- Identifying tools that were already established in our review of current practices around pupil voice gave us good grounding as to what might work and what had been done before.
- Having the space and time to allow staff to explore and adapt the tools in their own way promoted a sense of agency within school
- Embedding the concept of like/don't like throughout the school day with school staff highlighting to students when it was apparent they were enjoying or disliking something or someone also began to build on the premise that every child has the capacity to make and have preferences.

WHAT WERE THE BARRIERS?

- Understanding whether tools were being used meaningfully (were we gathering the real views of the child). It is always difficult to validate these but triangulating this with parent/teachers' views helped
- Staff having little time to commit to gathering student views – the activities had to be embedded well within the school system to allow teachers to dedicate time to this.

RESOURCES USED AND/OR PUBLICATIONS/WEBSITES TO SIGNPOST /REFERENCE:

- Clark, A. 2005. Ways of seeing: using the Mosaic approach to listen to young children's perspectives. (99+) (PDF) Ways of seeing: using the Mosaic approach to listen to young children's perspectives | Marlene Mboyo - Academia.edu
- Prizant, B.M., Wetherby, A.M., Rubin, E., A.C., Rydell, P.J. (2006) The SCERTS® Model: A Comprehensive Educational Approach for Children with Autism Spectrum Disorders. Brookes Publishing

10. Engaging a group of young people with moderate to severe learning disabilities in contributing to service development

Gemma Watts, Andy James and Jennifer McElwee, The Sun Class Young People's Group

PROJECT SUMMARY

A Participation group was set up in a specialist provision for young people with moderate to severe learning disabilities. The class teacher and teaching assistants were present and members of the health team facilitated the sessions.

We completed the sessions with the same class of young people (about 10) over the course of about a term. The project's ultimate goal was to support service development in regards to healthcare settings and enabling young people to have a voice about healthcare settings which they may visit for their own healthcare needs.

WHAT WE DID

For about a term, we met the group weekly for a session which lasted between 45 minutes to an hour. Initial sessions involved getting to know the young people and also supporting the young people to create their own identity 'Sharing Suns'. This involved each member of the group drawing their own pictures and then the pictures were amalgamated on a sun with each member's photograph being on the sun too. They also decorated their own t-shirts too. We also started the session with a theme song called 'Here comes the sun'.



Name:

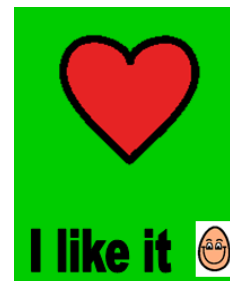
The sessions followed the same routine and structure. We introduced a sensory activity to encourage young people to tell us about whether they liked or did not like something (e.g. this included things such as a piece of fruit or some smelly aftershave). This activity was supported by visuals. It was also interactive and involved feedback to the whole group after each young person was able to express their choice. We also

Good practice examples from 'Hearing the Voice'

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

introduced a music activity which enabled the young people to tell us whether a piece of music made them feel happy or sad. Again, a fun interactive activity whilst gently encouraging young people to express how something made them feel.

The final aspect of the session was for the young people to tell us whether they enjoyed the session or not this involved the young people having their own photo and going to the sharing suns board and putting it in the area which corresponded to how they felt about the session.



The ultimate aim was to support the group to access an NHS health setting and for them to feedback to us what they thought about it. Unfortunately, due to restrictions this was not possible, however we were able to complete a session within class where young people were able to tell us by looking at photos what they thought of our clinic rooms and office spaces.

WHAT HELPED?

- **Routine and Structure:** The sessions always followed the same routine and structure. For consistency, the same members of health staff were present for the sessions.
- **Visuals:** Visuals also supported the session. A key element of the session was to support individuals to have a choice about whether they liked something or did not like something. Visual boards were created to support young people to show everyone whether they liked the item or whether they did not like the item. Visuals were also created to support the young people to understand our senses (touch, taste, hear, see and smell).

Good practice examples from ‘Hearing the Voice’

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- **Consistent Messages:** It also helped by providing the young people with consistent messages throughout the sessions. “You talk, we listen” which was reaffirmed throughout the sessions by the young people telling us their choices, we listen and acknowledged these choices whilst expressing that there was no right or wrong answer.
- **Sharing Suns Leader:** Each session a young person was chosen to support health staff with a job. The young people really enjoyed being selected. They were given a lanyard with a sharing sun’s leader star on. They were supported to facilitate and lead part of the session which included handing round the sensory items to the class.
- **Feedback:** The session always ended with us finding out from the young people whether they liked the session or they did not like the session. Again, a visual board with visuals of happy and sad were used to help us to find out whether they liked the session or whether they did not like the session.

WHAT WERE THE BARRIERS?

- **Accessibility for all children:** Within the class, there were a mixture of needs for all the children within the class. Some children were verbal whilst other children presented with limited to no verbal communication. Therefore, the varying levels of need within the class, needed us to think carefully about each child and consider how they can participate in the group. For example, one particular young person was 2:1 in class. We’re passionate about inclusivity and we thought carefully alongside the teacher about how he can participate in the group whilst also managing risk and safety. Therefore, adapting the class layout slightly so that he could participate as much as he could. Furthermore, a young person who appeared withdrawn from sessions, additional support was given to him so that he could take part.
- **Being mindful of allergies and food restrictions:** We had to be mindful of allergies and food restrictions for our sensory activity with the young people. However, developing a relationship with the young people’s class teacher was integral to our sessions.
- **Health and Safety:** The ultimate aim of the project was to hear the young person’s voices about a health care setting which the service accesses. Despite both health staff and school staff being on board and necessary procedures in place, other restrictions meant this was not able to take place.
- **Not enough time:** As health staff, we would have loved to have had the opportunity for more time with the young people. In the short space of time that we were working with the young people, the young people were becoming confident at being able to express whether they liked or did not like something. They were also able to express to us how a certain song made them feel. With the two particular young people we described, it was a privilege to see the young person become a part of the class. Also, for the other young person, he was becoming more confident in sessions and this was noted outside of these sessions too.

11. Understanding the experiences of children and young people with special educational needs in residential special schools

Vivian Hill, Elizabeth Pellicano, Scott Greathead and Lorcan Kenny, My Life at School

WHAT WE DID

We looked at how the rights of children and young people in residential special schools, with a wide range of disabilities and special needs were protected in line with the UNCRC -United Nations Convention on the Rights of the Child.

We developed a wide range of techniques and approaches to gain the voices of children in young people who were pre-verbal or had emerging language and communication skills. The work is all detailed along with visuals in the report which is available on the Children's Commissioner's website.

We visited 17 residential special schools across England, seeing 83 children and young people from 8 years 3 months - 19 years 8 months with a range of SEN and disabilities, speaking with 32 parents and 114 members of school staff, including teachers, care staff, and school-based therapists.

WHAT HELPED?

We used ethnographic approaches, graffiti walls, Mosaic, PECs, photovoice, talk and draw as well as interviews with those young people who were verbal.

WHAT WERE THE BARRIERS?

Very few. The issues around informed consent with over 16s being the biggest obstacle for these young people to have a voice.

RESOURCES USED AND/OR PUBLICATIONS/WEBSITES TO SIGNPOST /REFERENCE:

- Clark, A. 2005. Ways of seeing: using the Mosaic approach to listen to young children's perspectives. (99+) (PDF) Ways of seeing: using the Mosaic approach to listen to young children's perspectives | Marlene Mboyo - Academia.edu
- Cluely, V. (2016). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities*. 45; 1; 39-46.
- Greathead, S., Yates, R., Hill, V., Kenny, L., Croydon, A., & Pellicano, E. (2016). Supporting Children With Severe-to-Profound Learning Difficulties and Complex Communication Needs to Make Their Views Known: Observation Tools and Methods. *Topics in Language Disorders*. 36. 217-244.
- Hill, V., Croydon, A., Greathead, S., Kenny, L., Yates, R., & Pellicano, E. (2016). Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have 'a voice'. *Educational and Child Psychology*. 33.
- James, A. 2007 *Ethnography in the Study of Children and Childhood* (sagepub.com)
- Krisson, E., Qureshi, M. & Head, A. 2020. Adapting photovoice to explore identity expression amongst people with intellectual disabilities who have limited or no verbal communication. *Br J Learn Disabil*. 2021;00:1–11.
- Pellicano, L., Hill, V., Croydon, A., Greathead, S., Kenny, L., Yates, R. (2014). *My Life at School: Understanding the experiences of children and young people with special educational needs in residential special schools*. Office of the Children's Commissioner. London. *My Life at School* | Children's Commissioner for England (childrenscommissioner.gov.uk)
- Picture Exchange Communication System (PECs), PECS® | Picture Exchange Communication System (pecs-unitedkingdom.com)
- Office of the Children's Commissioner (2014) "They still need to listen more": A report about disabled children and young people's rights in England. London: Office of the Children's Commissioner.
[They_still_need_to_listen_more_a_report_about_disabled_childrens_rights_in_England.pdf](#) (childrenscommissioner.gov.uk)

12. Resources used and/or publications/websites to signpost /reference

Activities to do, always art equipment

Aman, M., Tassé, M., Rojahn, J. and Hammer, D. (1996). The Nisonger CBRF: A child behaviour rating form for children with developmental disabilities. *Research in Developmental Disabilities*, 17 (1), 41-57. Available at <https://www.corc.uk.net/resource-hub/working-with-learning-disabilities/>

Calm bags /Fiddly toys Calm bags – kits from Triangle or make your own [Resources | Triangle](#)

Cartmell, H. & Bond, C. (2015) What does belonging mean for young people who are International New Arrivals? *Educational & Child Psychology* Vol. 32 No. 2

Clark, A. 2005. Ways of seeing: using the Mosaic approach to listen to young children's perspectives. [\(99+\) \(PDF\) Ways of seeing: using the Mosaic approach to listen to young children's perspectives | Marlene Mboyo - Academia.edu](#)

Cluely, V. (2016). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities*. 45; 1; 39-46.

covid info;

https://nosycrow.com/wp-content/uploads/2020/04/Coronavirus_INS.pdf

[Easy read – A guide to your COVID-19 vaccination for people with a learning disability and their carers \(publishing.service.gov.uk\)](#)

Creating/tailoring books for individuals- personal story in narrative to help cope with eg missing people, can't see because of COVID, or is in prison. Using photos and their photos and their drawings – makes permanent (often forget ideas with any stress) and sharing with others experiences

Deighton et al. (2013). Me and My Feelings School measure. *Wellbeing Measurement Framework for Primary Schools*. EBPU/Anna Freud Centre. [primary-school-measures_310317_forweb.pdf \(corc.uk.net\)](#)

Frederickson, N., Simmonds, E., Evans, L. & Soulsby, C. (2007). Assessing social and affective outcomes of inclusion. *British Journal of Special Education*, 34, 105–115.

Free books from Timpsons with colourful pictures: **A Guide to Attachment; How to Create a Positive Future; Looking After Looked After Children** useful for issue specific consultations;

<https://www.timpson.co.uk/timpson-books/how-to-series.html>

<https://www.timpson-group.co.uk/alex-timpson-trust/free-books/>

Greathead, S., Yates, R., Hill, V., Kenny, L., Croydon, A., & Pellicano, E. (2016). Supporting Children With Severe-to-Profound Learning Difficulties and Complex Communication Needs to Make Their Views Known: Observation Tools and Methods. *Topics in Language Disorders*. 36. 217-244.

Good practice examples from ‘Hearing the Voice’

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Hill, V., Croydon, A., Greathead, S., Kenny, L., Yates, R., & Pellicano, E. (2016). Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have 'a voice'. *Educational and Child Psychology*. 33.



How it is. image vocabulary

<https://www.triangle.org.uk/files/2017-05/how-it-is-2002-an-image-vocabulary-for-children.pdf>

James, A. 2007 Ethnography in the Study of Children and Childhood [untitled \(sagepub.com\)](#)

Krisson, E., Qureshi, M. & Head, A. 2020. Adapting photovoice to explore identity expression amongst people with intellectual disabilities who have limited or no verbal communication. *Br J Learn Disabil*. 2021;00:1–11.

Midgen et al. (2019). ‘School for Everyone’: An exploration of children and young people’s perceptions of belonging. *Education and Child Psychology* 36 (2), 9-22.

Objects of reference Objects of Reference <http://www.totalcommunication.org.uk/objects-of-reference.html>

Office of the Children’s Commissioner (2014) “They still need to listen more”: A report about disabled children and young people’s rights in England. London: Office of the Children’s Commissioner.

[They still need to listen more a report about disabled childrens rights in England.pdf \(childrenscommissioner.gov.uk\)](#)

Pellicano, L., Hill, V., Croydon, A., Greathead, S., Kenny, L., Yates, R. (2014). My Life at School: Understanding the experiences of children and young people with special educational needs in residential special schools. *Office of the Children’s Commissioner*. London. [My Life at School | Children's Commissioner for England \(childrenscommissioner.gov.uk\)](#)

Picture Exchange Communication System (PECs), [PECS® | Picture Exchange Communication System \(pecs-unitedkingdom.com\)](#)

Prizant, B.M., Wetherby, A.M., Rubin, E., A.C., Rydell, P.J. (2006) *The SCERTS® Model: A Comprehensive Educational Approach for Children with Autism Spectrum Disorders*. Brookes Publishing

Resnick, M. D., P. S. Bearman, R. W. Blum, K. E. Bauman, K. M. Harris, J. Jones, J. Tabor, et al. 1997. “Protecting Adolescents from Harm: Findings from the National Longitudinal Study on Adolescent Health.” *JAMA* 278 (10): 823–832

Sussex Partnerships NHS Trust. *My Restraint Story*. Internal link when I’ve sent!

Talking Mats [Talking Mats | Improving communication, improving lives](#)

Tassé, M., & Aman, M. (1996) Nisonger Child Behavior Rating Form (NCBRF) Parent and Teacher versions. [Nisonger Child Behavior Rating Form - Nisonger Center \(osu.edu\)](#)

Team Epic, James, A. & Greedy, S. Presentation ‘We talk, you listen’ <https://www.bps.org.uk/member-microsites/dcp-faculty-people-intellectual-disabilities/events>

Two Way Street Intro video [Resources | Triangle](#)