



the british
psychological society
promoting excellence in psychology



Division of
Clinical Psychology



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*)

Stream 3 of the wider project: Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)
Good practice example from 'Hearing the Voice' of children and young people with moderate, severe or multiple and profound learning disabilities

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. Below we list 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 example from 'Hearing the Voice'

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

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 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

Good practice example from 'Hearing the Voice'

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

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.

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.

Good practice example from ‘Hearing the Voice’

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

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> <p>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.</p>

Good practice example from ‘Hearing the Voice’

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

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>
	I am going to say something about your intimate care plan.		
3	My intimate care plan means that people understand how to help me	<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>	Press each button on the communication aid and check for understanding

Good practice example 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 on communication aid	Description of process for this question
	Can you tell me if this is 'True', 'not true' or 'you don't know'		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. Return to any questions where it was not felt that young person understood and ask one more time.
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'	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'	
9	Would you like to take the Intimate care plan with you when you leave school? 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'	

Good practice example 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 on communication aid	Description of process for this question
10	Who would you like to see your intimate care plan? <i>(from a given selection)</i>	Yes No I don't know	Hold up intimate care plan proforma with their name on but no other details. Demonstrate an action of giving this to another adult. Show photos of parent/school staff/respite 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.
11	Which of these is important? I am going to show you all of them. Can you then pick the really important ones for you?	Include buttons that read out the following statements: <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 Give options: 'It is important', 'it is a bit important', 'it is not important' or 'I don't know'	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.

Good practice example 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 example 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 example 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'	
	S	Uses an eye gaze communication aid and also raises eyes for yes	"No" using Voca	

Good practice example 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
	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?' and T replied 'Yes'
	A	Flicks or raises eyes for 'yes'	'Yes'	Response not clear to me but

Good practice example 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
				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 'Yes', 'No' and 'I don't know'		
	T	Verbal response or switches pressed on Voca	'Good' using switch	

Good practice example 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
	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 selected 'Yes' using his eye gaze Voca	
	J	Uses an eye gaze communication aid and also raises eyes for yes		

Good practice example from 'Hearing the Voice'

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

SUMMARY OF REPONSES

	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

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

Good practice example from 'Hearing the Voice'

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

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.