Themes for hearing the 'voice' of 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)

June 2021

We did a thematic analysis on the submitted examples of 'good practice initiatives' that promote the 'voice' of children and young people with moderate, severe or profound and multiple learning disabilities (where 'voice' should be interpreted as meaning communication, in whichever form works best for the child or young person) and direct feedback from young people. The themes are presented in the following document.

Find more information here:
https://www.corc.uk.net/outcome-experience-measures/feedback-and-outcome-measures-for-children-and-young-people-with-learning-disabilities/

Table of Contents

THEMES

There were three main themes:

1. 'How children and young people can make an impact'
2. 'How to promote listening and conversation'
3. 'Barriers to conversation'.

THEME 1) HOW CHILDREN AND YOUNG PEOPLE CAN MAKE AN IMPACT

Children and young people's 'voices' can impact on:

*   Own life
*   Service development
*   Training and research
*   Community and cultural change

(i)   Their own life/care

Individual empowerment

"Asking about their own care, highlights to children and young people and their carers that they have something to say"

"Listening and offering daily realistic choices to children and young people also empowers them to communicate about important/bigger things in their life"

Highlights the 'right thing to do'

"Models and promotes the need, however difficult, to find a way to try and give a child/young person a voice"

"Models and promotes ways to modify approaches to not only elicit views, but also to ensure that informed consent is being given to participate. This is particularly pertinent for children and young people with physical difficulties, who could not, if they wanted to, take themselves away from some processes"

Increasing awareness in others

"Makes carers aware of children and young peoples' choices and what is going on for them and gives more information to carers"

(ii)   Service development

There was a range of initiatives promoting service development, including changes to the physical environment, staff recruitment and service literature.

Promoting change in services

"Children and young people were able to say what they liked and didn't like and changes were made as a result"

New processes

"Highlighted to management the need for dedicated time and resources, for example, the communication framework was built into the staff appraisal system"

Staff empowerment

"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"

"There was a more general sense of 'carrying' children and young people in staff's head, with staff thinking, what would the young people say about that?"

(iii) Training and research

Introducing a different lens

"Models good practice and what is achievable"

"Makes training meaningful and relevant"

"Begins to 'fill the gap' in current research"

Increasing Accessibility and Adaptations

"May require more thought and planning (eg. changing facilities in a hotel for conference presentation)"

"May require more time (eg. breaking down questions and teaching skills, asking questions of children and young people and systems of support)"

(iv) Community and Cultural Change

Within practitioners, co-production, teams, services, organisations and broader societal levels.

Catalyst for change

"Engaging in 'conversation' encourages further innovation and 'conversation'"

Challenging assumptions

"Asking about children and young people's preferences highlights to senior management that i) it is possible to ask and ii) it is useful to ask"

Highlighting strengths

"Asking what type of questions the staff felt the children and young people could answer independently challenged staff to consider how much they may use leading questions or make assumptions about what young people think or feel."

"Embedding the concept of like/don't like throughout the school day began to build on the premise that every child has the capacity to make and have preferences."

THEME 2) HOW TO PROMOTE LISTENING AND CONVERSATION

We used the **'Three Rs' framework** below from Beacon House to help think about themes related to promoting listening and conversation.

The first element **'Regulate'** is the base or foundation of the framework. This is needed before the second, **'Relate'**. Last is **'Reason'** – at whatever level and nature is appropriate for the child.

We drew upon information from the good practice initiatives summaries and direct feedback from children and young people we consulted with. Direct feedback from young people is presented in quotation marks and visuals.

Third: We can support the child to reflect, learn, remember, articulate and become self-assured.

Reason

Second: We must relate and connect with the child through an attuned and sensitive relationship.

Relate

First: We must help the child to regulate and calm their fight/flight/freeze responses.
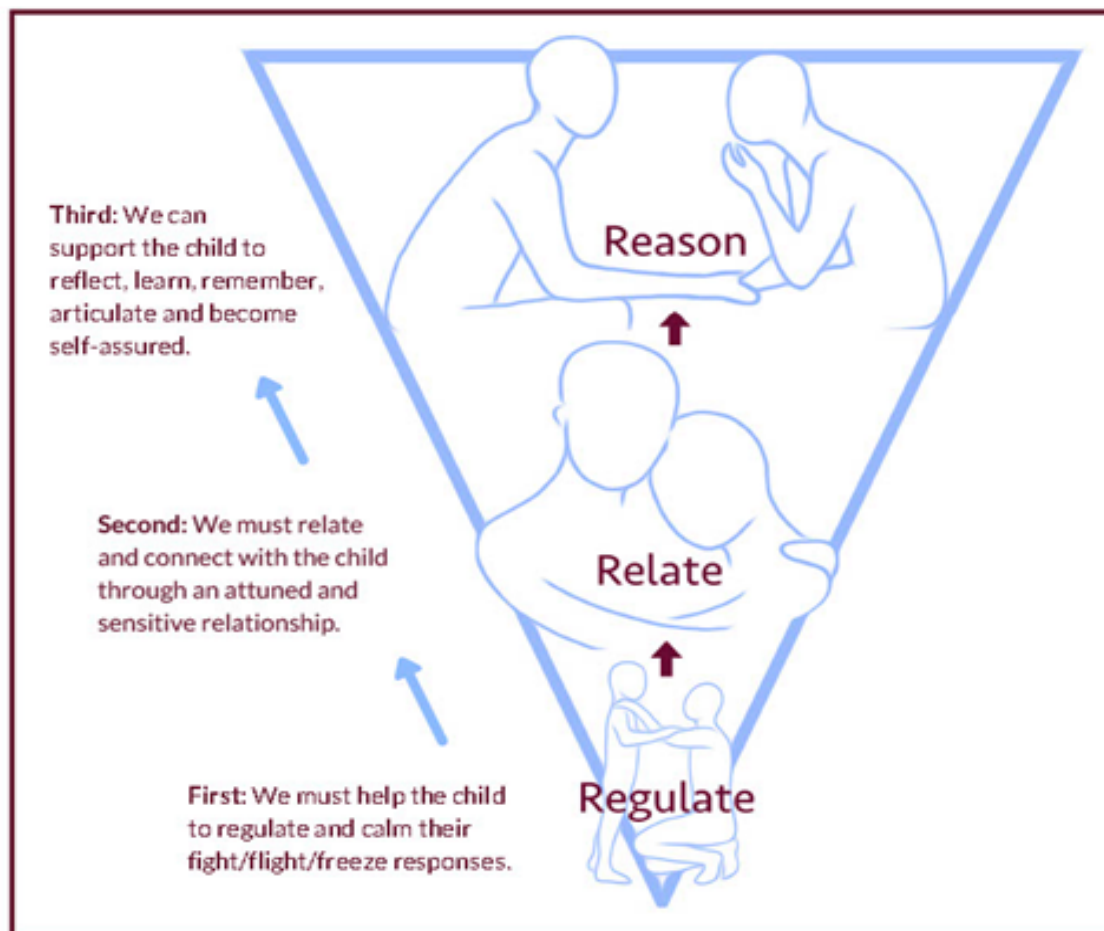
Regulate

Heading straight for the 'reasoning' part of the brain with an expectation of learning, will not work so well if the child is dysregulated and disconnected from others.

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1. Regulate – key elements from examples

- Routine and Structure
- Choice
- Visuals
- Consistent Messages

- Specific roles e.g. 'leader'
- Asking for feedback
- Attending to sensory and other needs
- Intensive interaction

Use   visuals   or   objects

"Making adjustments"
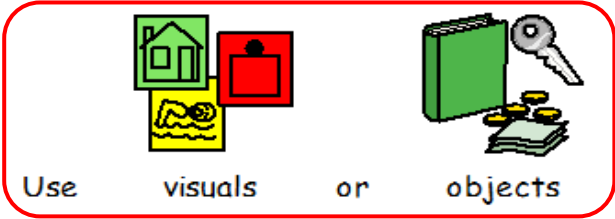
"An unequivocal code of conduct relating to notions of respect, tolerance and peaceful interactions for everyone, regardless of their identity, sexuality, gender identity or background"

"Safe spaces"

"Virtual sessions"

"Understanding what people would prefer within an environment"

"Protection of privacy"

"A quiet room"

"Being able to sign"

"One to one"

2. Relate – key elements from examples
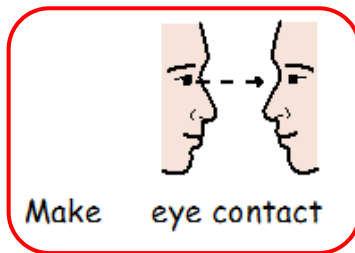
'Sender'

- Find out about the child/young person and work with people who know them well
- Think about how the child/young person communicates and use what works
- Use different forums eg. on own, alongside peers, with peers in group context, with support staff

'Receiver'

- Spend time in the child/ young person's environment before initiating 'conversation'
- Use different conversation facilitation methods e.g. role play, different senses, drawing, moving around the room
- Take time, persevere and notice 'sparkling moments'

"People asking me"

"Co-operation with like minded peers"

"Tolerant, friendly role models"

Make eye contact

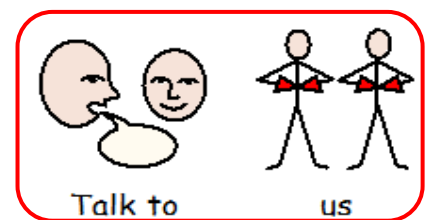*"Answer me and wait for me to answer and then reply"*

"It's largely about communication on both sides. What you can offer and what they would like you to offer, and work around that"

"Clear, unambiguous guidelines or instructions, straightforward, understandable communication"

Get on our level

"Listen properly and hear what I have to say"

Talk to us

3. Reason – key elements from examples

Children and young people may have had little experience of having their 'voice' heard, therefore it may be necessary to teach skills and enhance confidence alongside asking for feedback.

Two processes hand in hand:

- Teach skills and promote confidence
- Have a 'conversation'

Give us time to answer
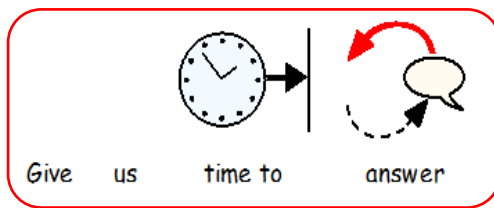
"Give me options, for example, this or that or something else"

"Self confidence"

"Frequent encouragement and guidance"

*"Involving us in every level of decision making in the service"*

"Allowing us to communicate in a way that is best for us and not forcing us to communicate in a 'neurotypical' way"

"When you ask for help they listen to you and then do it"

"They could do a lot more to focus on the positive aspects of neurodiversity, which is not spoken about as much"

"Repeating sentences, and staff start sentence, and young people finish it"

"No right or wrong answers"
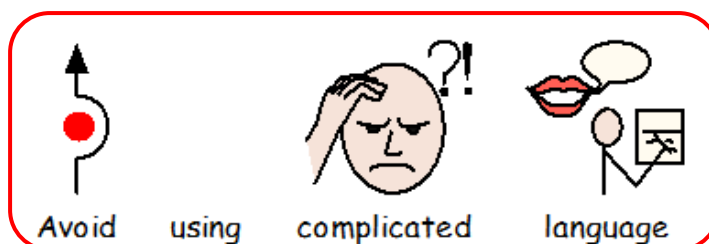
Avoid using complicated language

Contextual factors to promote listening and conversation - key elements of broader, multi-layered context and culture (social, attitudinal, spiritual, all aspects of diversity)

"Engagement with minority communities, especially at places of worship"

"Provisions for gender segregation or religious etiquette in activities for religiously conservative individuals"

"Outreach and dialogue; promoting greater understanding and respect"

"Myth-busting sessions"

"Distribution of guidance for parents, families and schools"

"Ethnic diversity, people from similar backgrounds or groups, no one stands out"

"Greater initiatives to raise awareness generally e.g. autism awareness week"

"Partnerships and endeavours with public or community figures; active participation with and support by the community"

"I think there needs to be more of a national movement. Something which is actively designed to give young people a voice, be it through visuals or text. Utilising social media would be a start"

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THEME 3) WHAT ARE THE BARRIERS?

Key elements from examples

- Being clear – is this the views of the child/young person, and what am I, and others, bringing to the conversation that might influence this?
- Communication limitations e.g. may only have tools to ask 'what' and not 'why'
- Practical barriers e.g. lack of time, illness, lack of transport, global pandemic… and attitudinal
- Needs individualistic approach – how to generalise
- Accessibility for all children within a group setting

"Work/life time constraints"

"Applying one size fits all approach for every autistic person rarely works, there needs to be understanding at all levels that my support needs will be different from other autistic people"

"Self-doubt"

"'Unwritten' rules or customs"

"Feeling burdensome, impatient authorities"

"Confusing, ambiguous guidelines or overly complex processes"

"Wearing masks as I can't hear them or it's delayed"

"Lack of diversity, 'invisible minority' syndrome"

"Forcing me to make eye contact does not help, nor does simply asking me to behave""