

Hearing the voice of children and young people with learning disabilities, their families and networks: how does /should this link with measuring outcomes

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It's me, learn to listen

Why is this important?

- Enshrined in Rights
- Enshrined in law (e.g. Children and Families Act 2014)
- Increase participation and empower
- Lead to improved, safer personalised support & services

Hearing the voice -- How?

Some examples of ways to listen and linked resources (from 27 organisations or people linked with so far)

- Use symbols and pictures

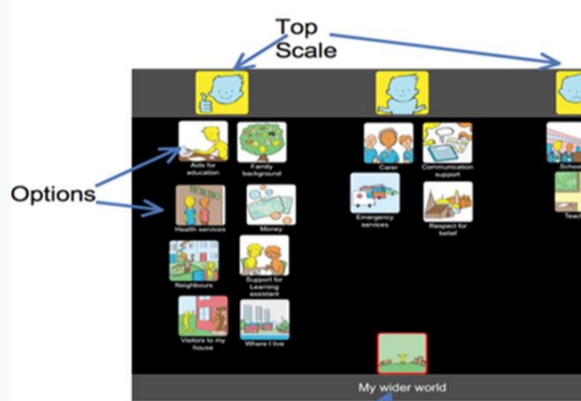
eg Widget/Communicate in Print; <http://www.widget.com/about/index.htm>



photosymbols: <http://www.photosymbols.com/>



- Talking Mats ↓ www.talkingmats.com



- Valuing the views of children with a learning disability ↑ (The Challenging Behaviour Foundation and Mencap) <https://www.challengingbehaviour.org.uk/learning-disability-assets/valuingtheviewsofchildrenwithalearningdisability.pdf>

- **This much!** David Glasgow– app; flexible, digital visual analogue scales – can customise with pictures, photos & words

Eg Bipolar scale with icons and context. The colours were selected to be relatively easily discriminated by individuals with red-green colour blindness.



- **“If you listen, you will hear us”** Leicester Partnership NHS Trust; video: https://www.youtube.com/watch?v=Hp4PW17U_h8

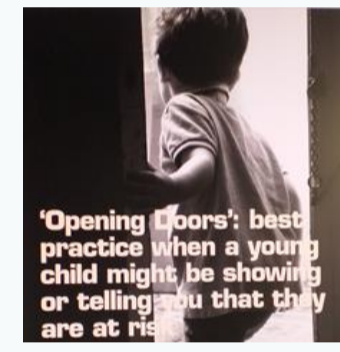
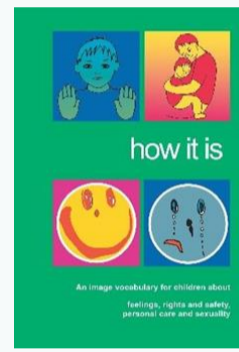
Shows how personalised ways of communicating- nonverbal gestures, day-to-day behaviours, e.g. eye-blink, change of colour in face can ensure all are included in decisions which impact on their lives & help evaluate and plan services



- CBF **“Stop, look, and listen to me”** – project based on Tizard centre method - 4 parts: Talking Mats Interview (see above), engagement in activities, structured observation (observable indicators), family/carer interview
- Nick Gore - **Goals and Outcomes For Intervention “GO-For-It”**: Child and family Views Project –child and parent interviews – use of Talking Mats, activities, observations (Gore & McGill, 2019)

Hearing the voice - For what?

- Personal views- goals, likes/dislikes, EHCP's, behaviour, opportunities, services
- ← see &
- Safeguarding/social and legal justice e.g. <https://www.triangle.org.uk/> for resources, training, investigative interviewing, intermediaries



and Me first communication framework, resources, training, <https://www.mefirst.org.uk/>

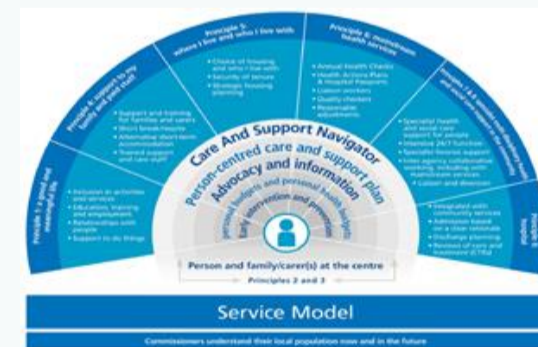
- Interviewing/selecting staff: Jeni M's projects
- Training:
- Practice development, evaluation & research

Measuring outcomes - How?

- Use, build on earlier consensus guidance on goals and measures



- Consider project survey responses (111 responses, 55 tools, 42 services willing to share further data, 19 with established children and young people & parent/carer groups)
- issues “symptoms” vs quality of life; measure against Building the Right Support principles? Or what?



- Share and build with national level eg Ask, Listen, Do; Transforming Care for Children, CBF; CDC; NHSE MHMDS



Reference:

Gore, Nick J. and McGill, Peter (2019) Making it Meaningful: Caregiver Goal Selection in Positive Behavioral Support. Journal of Child and Family Studies, online (online). pp. 1-10. ISSN 1062-1024.

The learning above is part of the project “Special measures?” - equality and diversity in feedback and outcome measures: progressing practice and practice-guidance on measures and methods for children and young people with learning disabilities (LD), their families and networks. January 2019-December 2020
 Jeni 2 -Anuerin Bevan UHB, Wales, lead for Profound and Multiple LD participation & service users. ; Neil3 –Worcestershire, lead for the measures and methods survey update and analysis ; Eric 5 -Lancaster and Sydney Universities, lead for interrogation of MCCS data on SDQ.; Nick 4 leads for CORC who host, collaborate with data analysis- existing and new data; Ro1 –BPS/DCP LD Network of CYPF Faculty/Tizard Centre Honorary Researcher, Project Manager’
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