Hearing the voice of children and young people with learning disabilities, their families and networks: how does /should this link with measuring outcomes
Ro Rossiter¹, Jeni McElwee², Neil Phillips³, Nick Tait⁴, Eric Emerson⁵

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
  [https://www.challengingbehaviour.org.uk/]
• Talking Mats ↓ [www.talkingmats.com]
  [https://www.challengingbehaviourfoundation.org.uk/talkingmats]
  [Option: a literal symbol card on which symbols from the NCI can be used to
  represent the child’s feelings, responses, wants, needs, likes, dislikes]…
• 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
• “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

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
Jeni² -Anuerin Bevan UHB, Wales, lead for Profound and Multiple LD participation & service users.; Nick T⁴ -Worcestershire, lead for the measures and methods survey update and analysis; Eric ⁵-Lancaster and Sydney Universities, lead for interpretation 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

Any queries, contributions, please contact Ro at: ro.rossiter@kent.ac.uk