Making Sense Together - Hearing the voice of children, young people and adults with learning disabilities

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5 Good Communication standards

1. There is good information that tells you how best to communicate with someone.

2. People are helped to be involved in making decisions about their care and support.

3. Others are good at supporting someone with their communication.

4. People have lots of chances to communicate.

5. People are helped to understand and communicate about their health.
Children, Young People and Adults with speech, language and communication needs are often …

• excluded from listening and feedback

• or included in tokenistic ways

• and risk their needs and opinions being assumed, misinterpreted or ignored
What do we need to do to hear their voices?

• Inclusive communication approaches
• Recognise that people understand and express themselves in different ways
• Give information in ways that meet communication needs
• Create a supportive and effective communication environments
• Use all available means of communication to understand and be understood
We need to know about **individuals' communication**

- How best to give and receive information
- Who, when and where to communicate
- The relationship between communication and behaviour or anxiety/distress
- Understand their likes and dislikes and review over time
- Seek feedback from a range of proxies to build a complete picture of views and preferences
Individuals should be able to say...

• Whatever communication methods work best for me are used and valued by others.

• People communicate effectively with me because of their underpinning knowledge, skills and attitude.

• People actively listen to me and take time to support my communication.

• I get the professional support I need to enable me to communicate to my full potential.

• The communication tools, techniques or technology I need is freely available to me throughout my life.

• Policies and strategies that affect me take into account my communication and include me in appropriate ways.
Goals and Outcomes For Intervention (GO-For-It): Child and family Views Project

Part of NIHR funded doctoral fellowship (PBS and children with IDD) – N.Gore (Tizard Centre)

Exploring:
• The impact of CB of individual and family quality of life
• Interactions between CB, QOL, Children’s pro-social behaviours and parenting behaviours
• Desirable behaviours for professionals an services

Identifying:
• Individual goals for the future relating to child’s behaviour (CB and PB), parenting behaviour, QOL and service support
Participants:

- **14** children and young people (4-15 years) with *range of intellectual and developmental disabilities* and *communication abilities* – all of whom had a history of *displaying CB* and were awaiting or *in need of service support*

- **12** Family carers of the above

Method:

**Parental interviews:**

Structured question areas based on an adapted version of Goldiamond’s constructional questionnaire (FQOL, CQOL, CB, PSB, PB, SQ)

Word-based Talking Mats procedure (frequency, impact, goals setting)
Child interviews

• Initial planning sessions with parents (communication and behavioural needs and strategies)

• Initial engagement session/time with child

• Tailored Talking Mats procedure (Activities, CB, PSB, PB, QOL, SQ)

• 1-2 sessions

After:

Feedback and checking during each session

Brief individualised report (areas of importance, current impact and difficulties, current strengths, service and professional behaviors required, goals for the future) – for planning and advocating for future support
Initial findings:

• It was possible to engage with children and young people with complex behavioral and communicative needs in meaningful ways – and they liked/found the methods and questions used helpful.

• Children and families were able to clearly identify things that were important to them, difficult for them and were strengths for them and to identify clear goals for positive future change.

• There were some very interesting interactions between these variables and the things people picked were often unexpected.

• Children and young people and families should routinely be supported (in ways tailored to meet their communication needs) to identify individual values, strengths, difficulties and needs and develop individualised goals based on these as a foundation for professional and service support.
Communicating with Mindy