Experiences of using a structured approach for assessment and goal-setting with children & young people with profound & multiple learning disabilities: A step towards increasing participation

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Background
- Participation is widely recognised as a priority for all children and young people.
- Participation is a complex construct, which influences and is influenced by intrinsic and extrinsic factors (Imms et al. 2017).
- Recent work highlights the value of understanding the lived experience of participation for young people with profound levels of disability (Powrie 2017). However, minimal research and resources exist to guide practice with this population of young people.

Context
- The Children’s Trust School is a specialist residential setting for children and young people with profound and multiple learning disabilities (PMLD). The therapy team work across residential and school setting using a multi-tiered approach.
- The occupational therapy team, together with multidisciplinary team colleagues, seek to increase awareness around the importance of participation and maximising opportunities for this. Recent review of team practice identified the potential value of following a joint goal-setting process, to include completion of a structured, participation-focused assessment.

Identifying needs
Due to range of communication difficulties the children and young people were unable to express themselves to identify their own goals, therefore we looked to those that know them the best:

Parents / Guardians
Teachers
Keyworkers (residential houses)
Therapists
Child/ Young Person

Assessment Experience
- The initial challenge centred on identifying a suitable assessment. At present there is limited research to support the use of a specific tool when goal setting with individuals with PMLD. We identified the following:
  - The Canadian Occupational Performance Measure (COPM)
  - Participation and Environment Measure for Children and Youth (PEM-CY)

Benefits & Challenges
- Conversations were facilitated around participation and creating a space where the potential for change is recognised.
- The COPM focuses on performance problems and skill acquisition and whilst this is relevant for some, it is not for all.
- The PEM-CY can be completed without a therapist present and it specifically focuses on participation, however some areas of participation were not relevant to all.
- Involving parent and families’ in the assessment process when their children live away from home was challenging as they were not always familiar with daily routines and issues.
- Barriers were identified when advocating a participation-focus with a population with complex medical needs.

Goal-setting:
- Identify need and broad goal area:
  - COPM
  - PEM-CY
- Define SMART goal
- Complete GAS paperwork
- Intervention(s)
- Evaluate progress
- Repeat outcome measures (annually)

Goal format
- Consideration of SMART (specific, measureable, achievable, realistic and timely) or SCRUFFY (student-led, creative, relevant, unspecified, fun, for, youngsters) goals
- ‘Goal Attainment Scaling (GAS) - Light’ version (Kiresuk and Sherman, 1969) was preferred to set formalised goals in view of capturing specific and measurable areas of participation

Conclusion
- It is well known that effective goal-setting will help focus treatment planning for therapeutic intervention. There are many available assessment tools and outcome measures that provide opportunities for participation focussed conversations, however, there is limited literature to support best practice when goal-setting with children and young people with PMLD.
- Through trialling different outcome measures at The Children’s Trust School we have identified benefits and challenges of using a combination of tools and also involving parents, families and the multi-disciplinary team in goal-setting conversations to support participation at home, school and in the community.

References
- Powrie, B. (2017)

www.thechildrenstrust.org.uk/presentationsandpublications