

# Guidance update and development:

## On the use of Routine Outcome Measures (ROM's) and feedback tools with Children and Young People with Learning Disabilities (LD), their families and networks

Prepared by: Ro Rossiter, Heather Armstrong, Duncan Law, Kate Martin, Neil Phillips, Julie Pill, Sara Sopena (with input from attendees at 2 events organized by London & SE CYP-IAPT Learning Collaborative, CORC and CYP-IAPT Outcomes and Evaluation Group (OEG), October 2014/March 2015)

### Summary of action points:

In the light of the considerations and caveats set out in detail below, it is recommended that: *Practitioners working with children and young people with learning disabilities, their families and networks use:*

1. **At least one standardized measure:** Revised SDQ and/or DBC, Nisonger or BPI as is clinically appropriate to the context - at least twice. SLDOM, whilst not standardized, also appears a clinically useful measure of change.
2. **Goals Based Outcome (GBO)** - at least twice
3. **CHI-ESQ** - at least once

### Considerations and Caveats leading to these recommendations

Building on the Law & Wolpert (eds, 2014) *Guidance on Using Outcomes and Feedback Tools with Children, Young People and Families*, this update draws on their principles of refining ROMS use over time and the need for clinical utility, discussion at the above two practice-sharing events and learning from more recent studies and projects in both the UK (Singh, 2014, Mulligan et al., 2014) and internationally (Norway- Halvorsen et al.; Australia - Emerson et al., personal communications)

The current perspective is:

- **ROM's are valuable tools.** They need to be fit for purpose and clinically meaningful so data can be collected, analysed and shared for diverse children and young people, including those with learning disabilities. Unfortunately, the current set of standard CYP-IAPT ROMS do not meet these criteria for most children and young people who have learning disabilities. Their

use will not be valid, and, therefore, it will not be ethical to require practitioners to use them with this client group to meet CYP-IAPT, CCG or service data requirements. There needs to be a way of utilising and reporting ROMS validly with Children and Young People with Learning Disabilities (LD), their families and networks.

- **Different services work with very different ranges of abilities**, use different terminology/definitions for different levels of ability/disability and have different amounts of experience with both CYP-IAPT ROMS tools and measures and/or other LD specific tools and measures. Hence, experience with use of measures and tools is highly varied, and generalized recommendations may not be helpful.
- Broadly, when considering CYP-IAPT ROMS, **emerging consensus suggests**:
  - **RCADS** is generally too developmentally advanced, especially for children and young people with substantial cognitive impairments/severe LD. It can be useful for some children and young people with mild LD/neurodevelopmental disorders. Therefore, use of RCADS would be as an exception rather than as a rule.
  - **the Revised SDQ** may be appropriate for use with a wider range of children and young people with LD than previously thought (Mulligan et al., 2014; Singh, 2014, 2015, SDQ norms for 2-4 year olds, ref). Two international projects are currently collecting and analysing SDQ data with children and young people with LD among other measures (Emerson et al. in Australia and Halvorsen et al. in Norway). Additionally, Emerson has suggested that analysis of the UK Millennium Cohort Study (MCS) SDQ parent and teacher data and cognitive levels will enable investigation of whether severity is associated with (1) the factor structure of the SDQ; (2) the internal consistency of SDQ sub-scales; and (3) correspondence between parent and teacher versions. Funding is being sought for this. Some services already collect, and others are volunteering (via Neil Phillips and Sara Sopena) to use SDQ for children and young people with LD, where it appears clinically useful, in a more systematic way. SDQ guidance on allowable rules for prorating if subscale items are deemed unscorable/inappropriate is given in Appendix 1. User feedback will be gathered (practitioner and family) and data be pooled for analysis to evaluate its use. Funding and practicalities are being investigated (and could include collaboration with the Australia and Norway data).
  - **The Sheffield Learning Disability Outcome Measure (SLDOM)**, completed with parents, appears clinically useful. It is collected by CYP-IAPT and shared with CORC for analysis. As a non-normed measure, SLDOM does not count in the 90% data target.
  - There are other well validated tools developed with and for children and young people with LD including those with severe and profound LD which are not currently in the CYP-IAPT ROMS data set. The most useful and well- used are the Developmental Behaviour Checklist, DBC (Einfield & Tonge, 1995, 2002; cost/ordering info in reference list), Nisonger Child Behaviour Rating Form (Aman et al. 1996; free), and Behaviour Problem Inventory (Rojahn et al., 2001, 2012a, 2012b; free). Some services are using one or more

of these. Systematic data collection and analysis of pooled data would enable evaluation to assist the development of guidance. Services have begun to volunteer to participate, through the surveys undertaken by Neil Phillips and Sara Sopena (Crawford, Phillips and Sopena, 2014, 2015). CORC may be able to assist with analysis where services are CORC members. Additional funding is being investigated.

- **The Goal Based Outcome (GBO)** tool (Law 2006) can be adapted to individuals' needs and there is general consensus that it is a clinically useful tool to be used with children with all ranges of LD. It may need to be used less frequently than every session. Practitioners should be allowed to use their judgement.
- **The service user feedback forms, CHI-ESQ**, can be used by parents and with creative use of visual supports, with children and young people with learning disabilities (depending of their level of ability). More thought is required around tools that a wider range of children and young people can use.

**For children and young people with severe and profound learning disabilities**, the challenges of seeking their views may be easily overlooked, and their voices unheard. Guiding principles for practitioners are suggested as:

- **Multiple perspectives:** gather information from multiple perspectives - parents/carers, school staff, siblings, as well as getting feedback from the child or young person directly (see next section). This allows triangulation of information to check change across a range of settings, and gives fuller, less partial views than a single perspective.
- **Multiple media:** try different media to capture views from multiple sources (see *BILD Communication Tools*) - clinical discussion, direct observation through individualised or guided checklists (such as Disability Distress Assessment Tool, DISDAT, (Regnard et al. 2007) which documents signs and behaviours when a person is content and when they are distressed), questionnaires, use of video/photos or, potentially, media such as bio-feedback (eg measuring heart rate and galvanic skin response) could be trialled as an indication of feedback, impact and change.
- **Multiple time points:** change should be measured over multiple time points – feedback is likely to be context and time specific. Measurement of multiple time points will allow for trends of change to be measured that may not be apparent from just two time points.
- **Resource:** it is acknowledged collecting such information is more complex and resource intensive than collecting information from children and young people with less severe communication difficulties. As a consequence, commissioners need to consider the resource needed to collect this information if there is a genuine

commitment to hearing the voices of some of the most vulnerable children in society.

### ***Future developments***

Using standardised measures is complex with children and young people who have LD, given the substantial developmental range they present with. However, this should not mean that they are excluded from using/sharing outcome measures. Practitioners will often identify creative ways to measure change to meet the individual's specific needs, and are keen to contribute and share data. It is essential that stronger dialogue is opened up between those who require data to measure outcomes and children and young people with LD, themselves, their parents, and the professionals who support them.

*A small task group from the practice sharing days is progressing data collection, sharing and funding plans in conjunction with CYP-IAPT, CORC and other key experts (eg Emerson and Halvorsen)*

### **References/Sources:**

The presentations from the 2 CYP-LD practice sharing events organized by London & SE CYP-IAPT Learning Collaborative, CORC and CYP-IAPT Outcomes and Evaluation Group (OEG), October 2014/March 2015 are available at: <http://www.corc.uk.net/ldworkshop/>

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CHI-ESQ available at <http://www.corc.uk.net/resources/measures/parent/>

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Developmental Behaviour Checklist - available from DBC@ monash.edu (DBC Starter Kit - 1 x DBC Manual plus 1 packet each of DBC-P and DBC-T checklists and scoresheets, \$130 Australian, approx. £65; pack of 10 checklists or 10 scoring sheets, \$10 approx £5.00)

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Emerson, E. 2005 Use of the Strengths and Difficulties Questionnaire to assess the mental health needs of children and adolescents with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 30, 1, 14-23.

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Download the Behavior Problems Inventory and BPI short-form free at:

<http://www.bps.org.uk/networks-and-communities/member-microsite/dcp-faculty-people-intellectual-disabilities/behavior-problems-inventory>

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SDQ website <http://www.sdqinfo.com/norms/UK3yearNorm.html> .

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## **Appendix 1:**

### **Information on allowable prorating for missing (inappropriate) items:**

**From:** [http://www.sdqinfo.com/py/sdqinfo/b3.py?language=Englishqz\(UK\)](http://www.sdqinfo.com/py/sdqinfo/b3.py?language=Englishqz(UK)) ; scoring instructions for SDQs for **4-17 year olds**, completed by parents, teachers or self-report

### **Scoring the Strengths & Difficulties Questionnaire for age 4-17**

The 25 items in the SDQ comprise 5 scales of 5 items each. It is usually easiest to score all 5 scales first before working out the total difficulties score. 'Somewhat True' is always scored as 1, but the scoring of 'Not True' and 'Certainly True' varies with the item, as shown below scale by scale. For each of the 5 scales the score can range from 0 to 10 if all items were completed.

*These scores can be scaled up pro-rata if at least 3 items were completed, e.g. a score of 4 based on 3 completed items can be scaled up to a score of 7 (6.67 rounded up) for 5 items.*

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