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Clinical Psychology



# SUMMARY: MEASURING OUTCOMES AND CHANGE FOR CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES; A CLINICAL PERSPECTIVE

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Stream 1 of the wider project: Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

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**Find more information here:**

<https://www.corc.uk.net/outcome-experience-measures/feedback-and-outcome-measures-for-children-and-young-people-with-learning-disabilities/>

## Summary: Measuring outcomes and change for children and young people with learning disabilities and their families; a clinical perspective

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## INTRODUCTION

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Over recent years much greater emphasis has been placed on the need for children and young people (CYP) and their families to be able to shape the mental health services that they access. Central to this was the Government's aim for services to become "rigorously focused on outcomes" by 2020 (Department of Health; DoH, 2015). However, for CYP with learning disabilities a number of obstacles have prevented this becoming a reality, including concern about the appropriateness of measures, a lack of consensus as to the best measures to use and the absence of meaningful, centralised data collection (Phillips et al., 2013; Rossiter et al., 2013).

To begin to address this, in 2011 a group of clinical psychologists organised workshops (Phillips, Sopena and Crawford, 2015; Rossiter, Phillips and Law, 2016), publications (Phillips et al., 2013; Rossiter et al., 2013; Rossiter et al, 2014; Rossiter and Armstrong, 2015) and a national survey of practitioners (Phillips, Sopena and Crawford, 2015; Rossiter, Phillips and Law, 2016). From these, emerged preliminary best practice guidance on the use of outcome measures with CYP with learning disabilities and their families (Rossiter et al., 2015).

To further extend this work, the British Psychological Society (BPS) funded a wider 'Special Measures' project, with a remit to identify the best ways of obtaining meaningful feedback generally from all CYP with learning disabilities and their families. This report describes Stream 1 of this project which aims to build further consensus around best practice in the use of formal outcome measures and to update the current guidance.

## METHOD

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A wide range of practitioners (working in UK services focusing on the mental health/behavioural needs of CYP with learning disabilities) were invited to take part in a much more comprehensive survey than in 2015 (Phillips and Demjen, 2019). Participants were asked to rate the clinical utility of a set of 11 'core' outcomes measures and any additional measures that they used, both from their own, and parents'/carers', viewpoints (how useful/easy to complete/well they capture change and any additional 'pros and cons'). They were also asked which CYP that they typically used each with in terms of the level of their learning disability and age. Quantitative and qualitative data was analysed and compared to the previous 2015 survey and the feedback from two national workshops.

**The core measures were identified from previous research (e.g. CORC, 2018) and included:**

### *Measures of symptoms/functioning*

- BPI-01 (Behavior Problems Inventory)
- CGAS (Children's Global Assessment Scale)
- DBC (Developmental Behaviour Checklist)
- Nisonger (Nisonger Child Behaviour Rating Form – Parent)
- RCADS-P (Revised Children's Anxiety and Depression Scale - Parent Version)
- SDQ Parent (Strengths and Difficulties Questionnaire - Parent Report), and
- SDQ YP (Strengths and Difficulties Questionnaire - Young Person Report).

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### Measures of Impact

- GBO (Goal Based Outcomes)
- SDQ Impact (Strength and Difficulties Questionnaire - Impact Supplement only), and
- SLDOM (Sheffield Learning Disability Outcome Measure).

### Evaluation of Service

- CHI-ESQ/ESQ (Experience of Service Questionnaire).

## FINDINGS

In total the responses from 95 practitioners were included in the final analysis. These practitioners came from a broad range of professions, services and regions of the UK and were using 49 different outcome measures, indicating the range necessary to meet the diverse and complex needs of CYP with learning disabilities and their families.

All 11 of the core measures were in more frequent use than any of the additional measures, supporting their selection. There was also a high degree of consistency in the most frequently used measures over time, with the same five core measures being the highest ranking in 2015 and 2019. However, there appeared to be a significant reduction in the use of measures over this time period.

Very few services submit outcome measure data to recognised central collection points such as the Mental Health Services Dataset (MHSDS) whilst nearly half hold on to their own data locally (an example of a service that analyses its own data is given in the Full Report).

Table 1 simplifies and summarises the main findings from the analyses of the core outcome measures across all aspects of the 2019 survey.

**Table 1: Summary of all analyses of the 'core' outcome measures to determine the most appropriate use of each**

MEASURE (number of respondents in brackets)	LEVEL OF LEARNING DISABILITY <sup>1</sup> (✓ indicates routinely used with this group, X indicates not)				CLINICAL UTILITY <sup>2</sup> (see key at foot of table)				QUALITATIVE ANALYSIS <sup>3</sup> Appropriate for use with CYP with learning disabilities?
	Mild	Moderate	Severe	Profound	Practitioner		Parent/carer		
					Useful?	Detects change?	Useful?	Easy?	
GBO (44)	✓	✓	✓	✓	✓✓	✓✓	✓✓	✓✓	✓
CHI-ESQ (24)	✓	✓	✓	✓	✓✓	?	✓	✓✓	✓
BPI-01 (14)	X	✓	✓	X	✓	✓✓	✓	✓	✓
Nisonger (8)	✓	✓	✓	✓	✓	✓✓	?	?	✓
RCADS-P (18)	✓	X	X	X	✓	?	✓	?	CYP with mild learning disabilities only
SLDOM (32)	✓	✓	✓	✓	✓	?	?	✓	✓
DBC (19)	X	✓	✓	X	✓	?	?	?	✓
SDQ Impact (17)	✓	✓	✓	X	?	?	?	✓✓	?
SDQ Parent (32)	✓	✓	✓	X	?	?	?	✓	CYP with mild learning disabilities only
SDQ YP (29)	✓	X	X	X	?	?	XX	XX	CYP with mild learning disabilities only
CGAS (9)	✓	✓	✓	X	XX	?	XX	?	X

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<sup>1</sup> 'routine use' is defined as where 50% or more of respondents use a measure with each subgroup

<sup>2</sup> clinical utility key – 95% confident that:

- ✓✓ both highly rated (mean score is >50/100) and better than at least some other measures;
- ✓ highly rated (mean score is >50/100);
- ? no firm conclusions can be drawn;
- X poorly rated (mean score is <50/100); and
- XX poorly rated (mean score is <50/100) and poorer than at least some other measures

<sup>3</sup> based on whether overall themes/comments indicated this

## DISCUSSION AND RECOMMENDATIONS

It is recommended that a combination of the following outcome measures is used **at least every six months and at closure** (*even though for some of the measures only weak supportive evidence has been found here, they may still be potentially useful*):

### 1. UNIVERSAL OUTCOME MEASURES (USE BOTH ACROSS AGES & ABILITIES):

- Goal Based Outcomes (GBO)
- Experience of Service Questionnaire (CHI-ESQ/ESQ)

**AND**

### 2. MEASURES OF IMPACT (SELECT AT LEAST ONE):

#### Some supportive evidence

- Sheffield Learning Disability Outcome Measure (SLDOM)

#### Weak supportive evidence

- Strength and Difficulties Questionnaire - Impact Supplement only (SDQ Impact)

**AND**

### 3. SPECIFIC OUTCOMES MEASURES (SELECT AT LEAST ONE from a or b as appropriate):

#### a. CYP with moderate to profound learning disabilities

##### Recommended (clear supportive evidence)

- Behaviour Problems Inventory (BPI-01)
- Nisonger Child Behaviour Rating Form (Nisonger)

##### Some supportive evidence

- Developmental Behaviour Checklist (DBC)

#### b. CYP with mild learning disabilities

##### Some supportive evidence

- Revised Children's Anxiety and Depression Scale - Parent Version (RCADS-P)

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### Weak supportive evidence

- Strengths and Difficulties Questionnaire - Parent Report (SDQ Parent), and
- Strengths and Difficulties Questionnaire - Young Person Report (SDQ YP)

### PLUS (OPTIONAL)

#### 4. ADDITIONAL OUTCOME MEASURES (for any other specific needs – use clinical judgement; evidence not evaluated here)

- see list in Appendix 4

Clinical judgement is important in selecting the most appropriate combination of formal outcome measures to use.

The findings from the quantitative and qualitative data in this and the previous 2015 survey, as well as the two national workshops, all largely support each other. This therefore lends confidence to the validity and coherence of the best practice guidance that emerges.

**Further consideration also needs to be given to the use of some of the measures in clinical practice, for example some may:**

- not measure change well but still be useful clinically (e.g. RCADS-P);
- feel more useful to practitioners than parents/carers, meaning that work may need to be done initially to help parents/carers understand the value of them (some services have set up ‘participation teams’ which may be a useful forum to do this; e.g. Nisonger);
- be difficult to complete meaning that parents/carers may need help from practitioners to do this (e.g. DBC).

All of these measures are for completion by parents/carers (other than the GBO which is intended to be based on a collaboration between practitioners, parent/carers and CYP, and the SDQ YP which is completed by CYP). This emphasises the importance of obtaining parents’/carers’ views on them. It also highlights the need to find individualised ways of ‘hearing the voice’ in obtaining meaningful feedback from CYP with more severe learning disabilities. It is important therefore to integrate the guidance here with that from Stream 3 of the project (McElwee, 2021).

**Practitioners also highlighted a number of issues that need addressing in using outcome measures in practice, including:**

- not just which but how outcome measures are used;
  - the impact of COVID-19 and remote working on families who are more likely to experience ‘digital poverty’;
  - the need to make measures available in easy-read formats and multiple languages; and
  - the culture around their use – practitioners and families need to see their value and usefulness in shaping services for CYP with learning disabilities.
- The need for a centralised collection point for data that can offer the meaningful analysis of the specific data for CYP with learning disabilities.

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There are a number of limitations inherent in the methodology of Stream 1 of the project, such as the lack of direct feedback from parents/carers themselves, but, given the coherence of the findings from a variety of sources and over time, the guidance appears to have significant validity. Future research may wish to address some of these limitations to develop this body of work further.

**Much more detail is available in the separate Full Report.**

## REFERENCES

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- CORC (2018). *Outcome Measures in Child and Youth Mental Health Services: your views*. London: CORC.
- Department of Health (2015). *Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing*. London: NHSE. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414024/Childrens\\_Mental\\_Health.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf)
- McElwee, J. (2021). *Hearing the 'voice' of children and young people with moderate, severe or multiple and profound learning disabilities*. Leicester/London.
- Phillips, N., Armstrong, H., Reid, C., Rossiter, R. and Morgan, S. (2013). Are we making a difference? Measuring the value of our work with children and young people with a learning disability and behaviour that challenges their families. *Intellectual Disabilities and Challenging Behaviour, ACAMH Occasional Paper No 32*. The Association for Child and Adolescent Mental Health (ACAMH).
- Phillips, N., Sopena, S. and Crawford, A. (2015). *The use of outcome measures with children/young people with more severe learning disabilities: what works in practice*. Presentation at CORC, CYP-IAPT London & SE Learning Collaborative and CYP-IAPT OEG (Outcomes and Evaluation Group) Learning Disability Workshop 12.03.2015.
- Phillips, N. and Demjen, E. (2019). *Outcome Measures for Children and Young People with Learning Disabilities*. San Mateo, California: SurveyMonkey Inc. ([www.surveymonkey.com](http://www.surveymonkey.com)).
- Rossiter, R., Armstrong, A., Morgan, S. and Phillips, N. (2013). Same or different? Measuring outcomes in children and young people with learning disabilities, their families and networks. *Child and Family Psychology Review*, 1, 84-92.
- Rossiter, R., Armstrong, H., Draper, E., Goodman, R., Morgan, S., Phillips, N., Pill, J., Reid, C., Sholl, C., Shrubsole, S., Turk, J. and Udwin, O. (2014). Learning Disabilities: collecting and use of feedback with children and young people with learning disabilities. In: Law, D. & Wolpert, M. Eds., *Guide to using outcomes and feedback tools with children, young people and families*. London: CORC, IAPT, Evidence Based Practice Unit, Anna Freud Centre, UCL. Available at: [https://www.corc.uk.net/media/2112/201404guide\\_to\\_using\\_outcomes\\_measures\\_and\\_feedback\\_tools-s-updated.pdf](https://www.corc.uk.net/media/2112/201404guide_to_using_outcomes_measures_and_feedback_tools-s-updated.pdf)
- Rossiter, R. and Armstrong, A. (2015). Using goals in clinical practice : Children and young people with learning disabilities, their parents/carers and networks. In Law, D. & Jacob, J. (Eds), *Goals and Goal*

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*Based Outcomes (GBOs) some useful information.* London: CAMHS Press. Available at:

<https://www.corc.uk.net/media/1219/goalsandgbos-thirdedition.pdf>

- Rossiter, R., Armstrong, H., Law, D., Martin, K. and Phillips, N. (2015). *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.* London & SE CYP-IAPT Learning Collaborative/CORC (Child Outcomes Research Consortium). Available at: <https://cypiapt.files.wordpress.com/2016/05/cyp-iapt-ld-roms-guidance1.pdf>
- Rossiter, R. Phillips, N. and Law, D. (2016). *Building momentum: who'd have thought ROM's could create such a buzz? Feedback and outcome measures and diversity: children with learning disabilities and neurodevelopmental conditions.* Workshop presentation at Children and Young People's Mental Health National Conference, Future In Mind from Vision to Implementation. London. Available at: [https://www.slideshare.net/cypucl/building-momentum-whod-have-thought-roms-could-create-such-a-buzz-workshop?qid=1e2f786f-883a-41a0-80e4-ca0e9e2067e4&v=&b=&from\\_search=4](https://www.slideshare.net/cypucl/building-momentum-whod-have-thought-roms-could-create-such-a-buzz-workshop?qid=1e2f786f-883a-41a0-80e4-ca0e9e2067e4&v=&b=&from_search=4)