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Clinical Psychology



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

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/>



Table of Contents

INTRODUCTION	3
METHOD.....	5
Views of practitioners.....	5
Survey.....	5
Participants	7
Data analysis	7
Workshops	8
Views of parents/carers	8
Collating data from services	8
FINDINGS.....	9
Views of practitioners - specific measures	9
Demographics	9
Measures used in practice	9
Level of learning disability and age	10
Clinical utility	11
Qualitative analysis	15
Views of practitioners - use of outcomes generally with CYP with learning disabilities.....	16
Barriers to using outcomes measures.....	16
Burden on parents	16
Inappropriate measures.....	16
Socioeconomic factors/COVID-19 remote working	16
What happens to the data?	16
Gaps in outcome measures.....	16
Views of parents/carers	17
Collating data from services	17
DISCUSSION AND RECOMMENDATIONS	19
Recommended use of outcome measures.....	19
RECOMMENDATIONS	21
Use of outcome measures with CYP with learning disabilities and their families	21
Further considerations	22
The use of outcome measures in practice	23
Data collection.....	24
Limitations.....	24
Building on these findings	25
REFERENCES.....	26
ACKNOWLEDGEMENTS.....	29
CITATION	29

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INTRODUCTION

Recent national drivers and best practice guidance have sought to place children and young people (CYP) and their families at the heart of shaping the mental health services¹ that they access. Central to this is the routine collection of feedback and outcomes, both to assess clinical effectiveness and to influence clinical practice at an individual and service level (Department of Health; DoH, 2015; Rossiter et al., 2015a). Reinforcing this message, the Government set an aim that by 2020 mental health services for CYP would be “rigorously focused on outcomes” (DoH, 2015).

Unfortunately for CYP with learning disabilities this is still far from reality for a number of reasons (Phillips et al., 2013; Rossiter et al., 2013). For example, there is concern about the meaningfulness and validity of the outcome measures available to meet the diverse and often complex needs of this group of CYP. When combined with the absence of specific national guidance for what are often small services operating in relative isolation, this has led to a lack of consensus as to the best measures to use.

When data is collected, practitioners can often feel torn between the need to make sure CYP with learning disabilities are included in this process and the recognition that many of the measures used are likely to be developmentally inappropriate (and therefore misrepresent their needs). In addition, they can feel that the specific needs of CYP with learning disabilities can get ‘lost’ amongst the much larger bank of data from other CYP. Also, when services do use measures developed specifically for CYP with learning disabilities, this data may not be collected by a central body as part of national dataset, such as the Mental Health Services Dataset (MHSDS).

Given the significant inequalities faced by CYP with learning disabilities in accessing effective psychological interventions (Lavis, Burke and Hastings, 2019) it is even more important that mental health services find meaningful ways to hear their, and their families’, voices.

In response to this, a group of clinical psychologists came together in 2011 to plan a series of initiatives focused on working towards a greater degree of consensus. These included:

- multidisciplinary regional and national workshops (Phillips, Sopena and Crawford, 2014; 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 2015 national survey of practitioners working in the area (Phillips, Sopena and Crawford, 2015; Rossiter, Phillips and Law, 2016) partly based on a similar study conducted by Morris, Bush and Joyce (2014) for adults with learning disabilities.

The consensus emerging as a result of these was captured in preliminary guidance on best practice in the use of outcome measures with CYP with learning disabilities and their families (Rossiter et al., 2015b). This highlighted the need for further work in this area, leading to an application for a grant from the British Psychological Society (BPS) in 2018 for a wider project. The proposed focus was the identification of best practice in obtaining meaningful feedback from CYP with learning disabilities more generally (including those with profound and multiple disabilities). The application was successful and this report describes Stream 1 of this ‘Special Measures’ project.

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

¹ the term 'mental health services', when used in relation to CYP with learning disabilities in this document, refers to the range of psychological, behavioural, intensive support and mental health services that seek to meet their needs

Stream 1 focuses on the clinical utility of the formal outcome measures in use in mental health services with CYP with learning disabilities and their families; the main aim being to update and extend the existing consensus-based best practice guidance through:

- canvassing the views of practitioners working in these services using a more comprehensive national survey than in 2015;
- asking respondents to rate and comment on the relevance and usefulness of the measures they currently use from their own and parents'/carers' perspectives; and
- combining these findings with the discussions from two subsequent interactive workshops.

Two further elements were also planned to extend the previous work even further:

- obtaining direct feedback from parents/carers on the outcome measures in use; and
- collating outcome data from services to enable benchmarking, analysis of any measured change, and a comparison with clinical opinion of change (the face validity of each measure).

However, the COVID-19 outbreak began mid-way through the project and radically changed families' (and services') priorities and severely limited progress in these additional areas. This is discussed more fully later. It has been possible, however, to report the analysis of extensive data collection from one service as a case study.

Gathering the views of CYP with learning disabilities themselves was outside the scope of this project Stream. The reasons for this are that firstly only one of the measures identified as being in common use previously requires CYP to self-report. The remainder are all completed by parents/carers, or in one case, practitioners. Secondly, Stream 3 of the project ('Hearing the Voice'; McElwee, 2021) focuses exclusively on ways of obtaining feedback from CYP of all abilities but particularly those with profound and multiple disabilities. This deserved careful consideration in its own right. The findings from both streams therefore need to be integrated to form coherent guidance.

Although the aim of this project is to help consolidate the consensus around the use of outcome measures, there is an inherent recognition that the resulting updated guidance will be dynamic and change as practice and policy develop.

METHOD

Views of practitioners

Survey

A survey was constructed combining some elements of the original 2015 survey (Phillips, Sopena and Crawford, 2015; Rossiter, Phillips and Law, 2016) and the outcomes questionnaire used in the NHS England-funded, 2018 Child Outcomes Research Consortium (CORC) survey of CYP and parents/carers accessing child and youth mental health services (CORC, 2018). However, the current survey (Appendix 1) was extended to enable a more comprehensive assessment of practitioner views. The key elements were:

- demographic information about the practitioner and their service, and
- the outcomes they used routinely.

For each outcome measure there were follow-up questions (generating quantitative data) about:

- which CYP the practitioner typically used the measure with:
 - level of learning disability of the CYP², and
 - age group.
- practitioner ratings of clinical utility on a scale from 0-100 (generating further quantitative data):
 - how useful the practitioner found each measure and how well it detected change, and
 - how useful and easy to complete they thought parents/carers/young people found it.
- pros and cons of each measure (generating qualitative data); and
- further questions about data collected/submitted and any direct feedback gathered from parents/carers/CYP.

To retain anonymity the provision of contact details was optional.

Eleven 'core' outcome measures were included in the survey (with the option for practitioners to add up to five more) capturing individual and systemic change. These were identified by their inclusion in the current best practice guidance (Rossiter et al., 2015b) and/or the most popular responses from learning disability services in the recent CORC survey (CORC, 2018).

The core measures included were:

Measures of symptoms/functioning

- BPI-01 (Behavior Problems Inventory; Rojahn et al., 2001)
- CGAS (Children's Global Assessment Scale; Shaffer et al., 1983)
- DBC (Developmental Behaviour Checklist; Einfield and Tonge, 1995)
- Nisonger (Nisonger Child Behaviour Rating Form – Parent; Aman et al., 1996)
- RCADS-P (Revised Children's Anxiety and Depression Scale - Parent Version; Chorpita et al., 2000)
- SDQ Parent (Strengths and Difficulties Questionnaire - Parent Report; Goodman; 1997), and
- SDQ YP (Strengths and Difficulties Questionnaire - Young Person Report; Goodman, 1997).

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Measures of Impact

- GBO (Goal Based Outcomes; Law and Jacob, 2015; Law, 2019)
- SDQ Impact (Strength and Difficulties Questionnaire - Impact Supplement only; Goodman, 1997), and
- SLDOM (Sheffield Learning Disability Outcome Measure; Sheffield Children's NHS Foundation Trust/CORC).

Evaluation of Service

- CHI-ESQ/ESQ (Experience of Service Questionnaire; Brown et al., 2014).

Once approved by the Project Management Group the survey was uploaded to SurveyMonkey (Phillips and Demjen, 2019).

² No formal individual definitions were given for 'mild', 'moderate', 'severe' and 'profound' learning disabilities - their use is therefore as respondent-defined relative terms

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Participants

In June 2019 an email was circulated around the BPS's Division of Clinical Psychology/CYP and Families Faculty/Learning Disability Network. It invited practitioners working in services focusing on mental health/behavioural issues, to complete the online survey and forward it to others working in the area (Appendix 2). In addition, participants from the 2015 survey who had consented to being contacted were also emailed. Initially a three week deadline was set but this was subsequently extended to enable more respondents to participate.

The survey was also heavily promoted through the websites and social media platforms of the BPS and CORC. To maximise equality of inclusion in terms of the geographical spread of services further services across the UK were identified by using internet searches and visiting local and national directories for registered services for CYP with learning disabilities.

In total N=130 respondents attempted to complete the survey of which 95 respondents were included in the final analysis. The primary inclusion criterion was a complete set of responses on the follow-up questions for at least one of the 11 core or five additional outcome measures included in the survey (N=109 in the more basic 2015 survey although inclusion criteria were not as stringent). Missing data was coded with specific labels in order to identify exclusion of items from the overall analysis.

Data analysis

Quantitative

Due to the relatively small number of responses on several sets of the follow-up questions on some outcome measures, descriptive statistics were used to analyse the quantitative data. However, 95% confidence intervals were calculated for the clinical utility mean rating scores, to lend greater validity to the interpretation of any differences. Cleansing of the data and required transformations were applied where necessary, and analysis of data was conducted using the IBM statistics software SPSS v25.

As part of the analysis cut-off points (such as '50% or above') were introduced for some of the data. Whilst not necessarily statistically rigorous this simplification of the data allowed basic conclusions to be drawn more easily. Data were also compared to that from the previous 2015 survey (Phillips, Sopena and Crawford, 2015; Rossiter, Phillips and Law, 2016) where corresponding questions were asked, in order to assess consistency over time.

Qualitative

Qualitative comments were analysed using thematic coding analysis (Braun & Clarke, 2006). Data segments were coded with a label and organised into a number of themes for each outcome measure. These themes were also compared to the findings from the quantitative data, and also the qualitative data from the 2015 survey, to investigate the degree of consistency between them.

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Workshops

The preliminary results from the survey were presented at two online workshops in early 2021 attended by more than fifty practitioners in the field. Participants shared examples and observations from their own practice in the online chat thread and small breakout groups, in relation to:

- what they were doing to measure outcomes and change; and
- how COVID-19 and diversity/equality issues have impacted on this.

The themes emerging from these discussions are included in the analysis to both enhance and update the survey data. There was no formal qualitative analysis of the comments.

Views of parents/carers

In addition to the indirect views of parents/carers reported by practitioners in the survey, attempts were made to contact those respondents who reported that they either already collected feedback from parents/carers, or were willing to gather it from groups that could give such feedback (with their consent). The number contacted was limited by the fact that leaving contact details on the survey was necessarily optional. During the timeframe of the project no responses were received, which is likely to be because of the shift in priorities caused by the COVID-19 outbreak. The Project Management Group considered that to gather this data ourselves would require face-to-face meetings with families due to the sensitivity of some of the measures. The Group felt that this was neither feasible, nor ethical, to attempt in the current climate.

Collating data from services

Practitioners who reported in the survey that they might be willing to share the outcome data that they collected (with sufficient safeguards in place) were contacted where contact details were provided. However there was only one response during the timeframe of the project (again it is likely that COVID-19 impacted on this) and despite some further contact it was not possible to pursue this further before the deadline.

However, five and a half years of data had been collected and analysed by the Worcestershire Learning Disability CAMHS service (in which one of the authors works). This analysis has therefore been included as an example of the clinical usefulness of data produced by some of the measures discussed here.

FINDINGS

Views of practitioners - specific measures

Demographics

The demographic data from the survey respondents included in the final analysis (N=95) are shown in the graphs in Appendix 3. The data demonstrates that:

- practitioners came from a wide range of professions and backgrounds with the majority being psychologists (61%) or nurses (20%), which probably reflects the forums through which the survey was circulated;
- practitioners worked in a range of mainstream and learning disability services indicating the variety of services attempting to meet the mental health/behavioural needs of CYP with learning disabilities. Most (53%) worked in Learning Disability CAMHS services;
- all sectors were represented in the survey although 83% of respondents worked in NHS services; and
- all four countries within the UK were represented in the survey in proportions very similar to their respective populations (although Scotland was slightly under-represented). Within England all regions were represented.

Measures used in practice

Figure 1 shows the percentage of survey respondents routinely using each of the 11 core outcome measures in their practice. The graph also shows the comparable data from the 2015 survey where this is available. There is a high degree of consistency in the most frequently used measures with the highest ranking five remaining the same (the SDQ YP was not included in the 2015 survey):

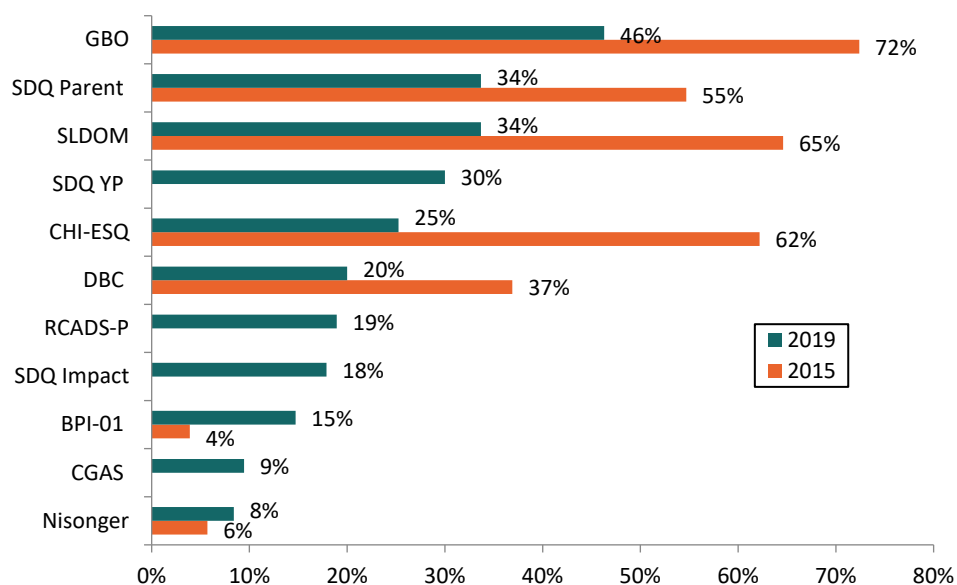
- GBO
- SDQ Parent
- SLDOM
- CHI-ESQ, and
- DBC.

In total 38 additional measures were being used by practitioners. All of these were used less frequently than all of the 11 core measures, reinforcing the appropriateness of their selection. The full quantitative and qualitative data from the additional measures is presented in Appendix 4 but is excluded from more detailed analysis due to the small numbers involved. These measures tend to focus on more specific areas of measurement.

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Figure 1: Percentage of respondents using each of the 'core' measures; current 2019 survey (N=95) compared to 2015 survey (N=109) where a comparison is available.



Interestingly all of the five highest ranking measures included in both the 2015 and 2019 surveys have seen a significant deterioration in their use in the intervening four years. Given that this cannot be accounted for by the widespread use of additional measures (or by the COVID-19 pandemic given the 2019 survey preceded it), this would seem to indicate a sharp fall-off in the use of outcome measures with this group of CYP generally.

Level of learning disability and age

Appendix 5 shows which specific sub-groups of CYP practitioners typically use each outcome measure with, in terms of the level of their learning disability (as defined by respondents) and age group. Colour-coding the data according to whether 50% or more of total respondents for each measure use it with each sub-group (blue) or less than 50% (grey), gives an indication of groups that each measure is used 'routinely' with (Table 1).

Combining this information with the qualitative analysis in Appendix 6 would suggest that practitioners tend to use the core measures in specific ways.

- All measures are used routinely with 5-17 year olds.
- Very few measures are used with 0-4 and 18-25 year olds.
- A group of measures are used with CYP of all abilities (GBO, CHI-ESQ, Nisonger, SLDOM; however the result from the Nisonger must be interpreted with some caution given the small numbers of respondents involved).
- Some are used specifically with CYP with more severe learning disabilities (DBC, BPI-01) – these are behavioural in nature and designed specifically for people with learning disabilities.
- The six measures mentioned are also the ones identified in the qualitative analysis as being most appropriate for use specifically with CYP with learning disabilities, adding further weight to these findings.
- Relatively few measures are used routinely with CYP with profound learning disabilities.

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

- The RCADS-P is only used routinely with parents/carers of CYP with milder learning disabilities – it is based on mental health symptoms including questions about their CYP’s internal world (how they think and feel). Again the qualitative analysis supports this finding with respondents not feeling that it is appropriate for CYP with moderate to severe learning disabilities.
- The only CYP self-report measure (SDQ YP) is mainly used with CYP with milder learning disabilities. The qualitative data supports this in that practitioners feel that the SDQ YP is too complex and abstract for CYP with significant learning disabilities to use and that it does not capture their needs.

Table 1: Colour-coded table showing the sub-groups of CYP that 50% or more of respondents use each ‘core’ measure with (blue) and less than 50% (grey).

Outcome measure	Level of learning disability (blue = used ‘routinely’)				Age group (years) (blue = used ‘routinely’)			
	Mild	Moderate	Severe	Profound	0-4	5-11	12-17	18-25
GBO	Blue	Blue	Blue	Blue	Grey	Blue	Blue	Grey
CHI-ESQ	Blue	Blue	Blue	Blue	Grey	Blue	Blue	Grey
Nisonger	Blue	Blue	Blue	Blue	Grey	Blue	Blue	Grey
SLDOM	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Grey
SDQ Impact	Blue	Blue	Blue	Grey	Grey	Blue	Blue	Grey
SDQ Parent	Blue	Blue	Blue	Grey	Grey	Blue	Blue	Grey
CGAS	Blue	Blue	Blue	Grey	Grey	Blue	Blue	Grey
DBC	Grey	Blue	Blue	Grey	Grey	Blue	Blue	Grey
BPI-01	Grey	Blue	Blue	Grey	Grey	Blue	Blue	Blue
RCADS-P	Blue	Grey	Grey	Grey	Grey	Blue	Blue	Grey
SDQ YP	Blue	Grey	Grey	Grey	Grey	Blue	Blue	Grey

The relatively infrequent use of measures with CYP with profound learning disabilities and those who are either under 4, or between 18 and 25, years old may be due to services not working routinely with these CYP.

Clinical utility

To facilitate more robust findings, 95% confidence intervals (the range within which we can be 95% confident that the true mean lies) were calculated for the mean ratings for each measure on each of the clinical utility questions. This takes account of both the variation within the ratings and the number of respondents for each measure. As a result two separate comparisons could be made:

- whether the range of the confidence interval for each measure was fully above or below a cut-off score chosen as 50 (out of 100), representing 95% confidence that the mean score for a measure represented a positive or negative clinical utility rating (where a positive rating was interpreted as meaning it was useful, detected change well or was easy to complete); and
- whether there was any overlap between the confidence intervals for the means of different measures; no overlap indicated confidence that there were significant differences in their means (and that, for example, one was significantly more useful than another)

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

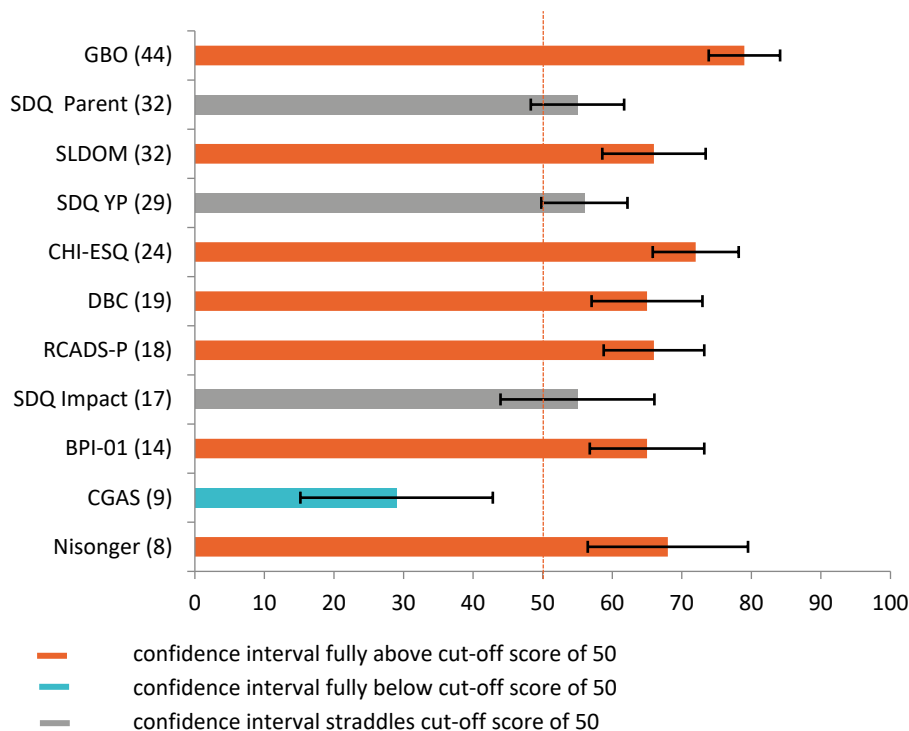
Analysis of the data allows the following conclusions to be drawn in relation to each clinical utility factor (no conclusions are made for measures where confidence intervals do not fully lie above/below a score of 50 or where they overlap with other measures).

Usefulness for practitioners (see Figure 2)

We can be confident that:

- GBO and CHI-ESQ are rated as **useful** for practitioners and **more useful** than some of the other measures (this is supported by the qualitative findings in Appendix 6);
- SLDOM, DBC, RCADS-P, BPI-01 and Nisonger are rated as **useful** for practitioners (broadly consistent with the qualitative data although the appropriateness of the RCADS-P for CYP with more significant learning disabilities is questioned); and
- CGAS is rated as **not useful** and is in fact **the least useful** measure for practitioners (consistent with the qualitative feedback).

Figure 2: Graph of mean scores of practitioner-rated clinical utility for each 'core' outcome measure – how useful PRACTITIONERS find the measure (0-100 where 100 is the most positive; number of respondents in brackets next to each measure; 95% confidence intervals also included).



Detection of change (see Figure 3)

We can be confident that:

- GBO, BPI-01 and Nisonger are rated as **good at detecting change** and **better** than some of the other measures (a finding consistent with the qualitative analysis although the GBO may struggle to track small changes).

Usefulness for parents/carers (see Figure 4)

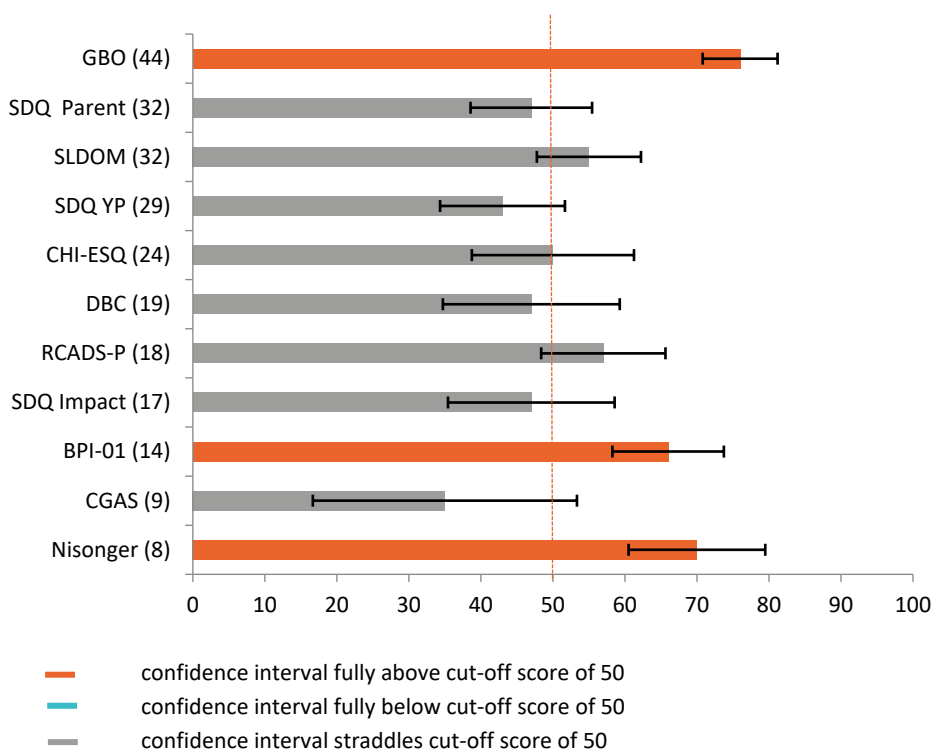
We can be confident that:

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

- GBO is rated as **useful for parents/carers** and **more useful** than most other measures (consistent with the qualitative data);
- CHI-ESQ, RCADS-P and BPI-01 are rated as **useful for parents/carers** (some consistency with qualitative data, for example that the CHI-ESQ has space for narrative comments by parents, although the usefulness of the RCADS-P for CYP with more significant learning disabilities is questioned); and
- SDQ YP and CGAS are rated as **not useful for parents/carers** and are **less useful** than most of the other measures (consistent with the qualitative data, for example the appropriateness of the SDQ YP for CYP with learning disabilities is questioned).

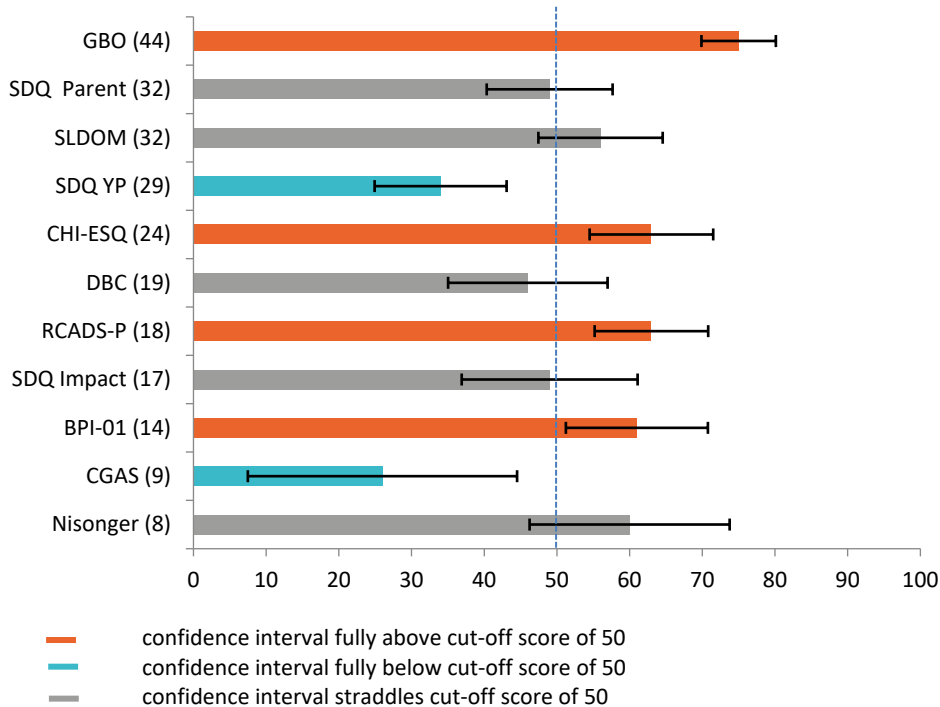
Figure 3: Graph of mean scores of practitioner-rated clinical utility for each 'core' outcome measure – how well PRACTITIONERS think the measure detects change (0-100 where 100 is the most positive; number of respondents in brackets next to each measure; 95% confidence intervals also included).



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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Figure 4: Graph of mean scores of practitioner-rated clinical utility for each 'core' outcome measure – how useful PARENTS/CARERS (and CYP for the SDQ YP, practitioner for the CGAS) find the measure (0-100 where 100 is the most positive; number of respondents in brackets next to each measure; 95% confidence intervals also included).



Ease of completion (see Figure 5)

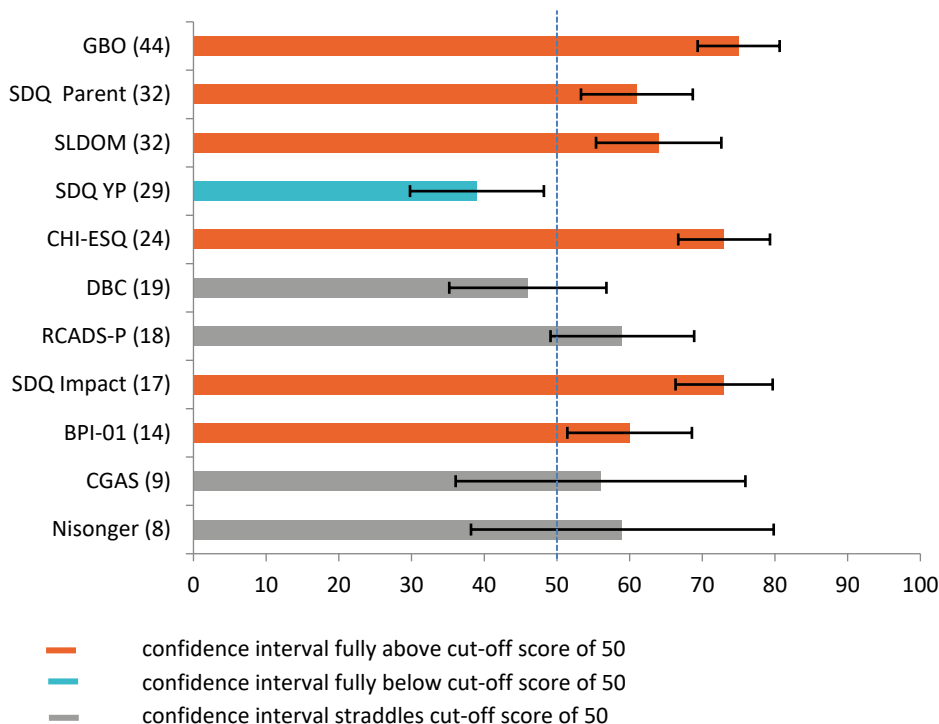
We can be confident that:

- GBO, CHI-ESQ and SDQ Impact are rated as **easy to complete for parents/carers** and **easier** than some of the other measures (all consistent with the qualitative data);
- SDQ Parent, SLDOM, BPI-01 are rated as **easy to complete** (again, consistent with qualitative feedback although some of the language of the SLDOM may be confusing, such as the use of double negatives); and
- SDQ YP is rated as **not easy to complete** by CYP and **less easy to complete** than most of the other measures (although the qualitative feedback indicates that it is quick and easy to complete, the questions may be too complex and abstract for CYP with learning disabilities).

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Figure 5: Graph of mean scores of practitioner-rated clinical utility for each 'core' outcome measure – how easy to complete PARENTS/CARERS (and CYP for the SDQ YP, practitioner for the CGAS) find the measure (0-100 where 100 is the most positive; number of respondents in brackets next to each measure; 95% confidence intervals also included).



Qualitative analysis

As already mentioned the qualitative data in Appendix 6 largely supports the quantitative analysis. We can tentatively conclude that four groups of measures are identified in the qualitative analysis:

- Those that are felt to be appropriate for use with CYP with learning disabilities:
 - GBO
 - CHI-ESQ
 - SLDOM
 - DBC
 - BPI-01, and
 - Nisonger.
- Those that may be appropriate but perhaps with some reservations:
 - SDQ Impact.
- Those that may be appropriate for CYP with milder learning disabilities:
 - SDQ Parent
 - RCADS-P, and
 - SDQ YP.
- Those that are not felt to be appropriate for CYP with learning disabilities
 - CGAS

Views of practitioners - use of outcomes generally with CYP with learning disabilities

The feedback from the two workshops held in early 2021 (where the initial findings of the project were presented) was broadly consistent with the 2019 survey data. In addition, issues such as the impact of COVID-19 and access and diversity more generally were raised as detailed below:

Barriers to using outcomes measures

- Language barriers can be an obstacle especially with measures with more complex language (for example the SLDOM) – potential solutions include:
 - using an interpreter in sessions (however this can significantly increase the length of the session while decreasing the amount covered due to the process of translation), and
 - translating measures into other languages.

Burden on parents

- Difficult giving additional work to parents on top of all other responsibilities (especially during the COVID-19 pandemic).

Inappropriate measures

- Embarrassing to give parents measures that practitioners know are not appropriate for their child.

Socioeconomic factors/COVID-19 remote working

- People in lower socioeconomic groups often lack the equipment/knowledge/space to access virtual support.
- Those excluded risk feeling even more excluded during the pandemic due to the reliance on virtual work - recognition of digital poverty and language difference.
- More difficult to work remotely including completing outcomes measures – harder to build trust.

What happens to the data?

- Who the measures are actually useful for and to what extent are they used to shape services and practice?
- Cost savings can be a focus for managers whereas practitioners may want to demonstrate clinical outcomes.
- Need for bottom up flow of information – need for best practice guidance around outcome measures to demonstrate its importance to those above.

Gaps in outcome measures

- Discussed the lack of recognised quality of life measures for use with CYP with learning disabilities.
- Talked about the inability of measures to capture the qualitative experiences of people such as the quality of relationships.
- Some services are setting up participation teams with parents/carers to gather feedback about outcome measures and share why practitioners feel they are important.

Views of parents/carers

Practitioners' perceptions of the views of parents/carers about specific outcome measures were captured in the survey through quantitative and qualitative data. However, as already stated, it was not possible to gather direct feedback from parents/carers within the timeframe of the project, largely due to the COVID-19 outbreak. Practitioners at the two workshops echoed the view of members of the Project Management Group that this feedback needed to be gathered face-to-face due to the sensitive nature of the issues raised in some of the measures. Findings from Stream 3 of the project (McElwee and Rossiter, 2021) support the importance of a collaborative approach to gathering feedback.

Collating data from services

Appendix 7 contains a brief summary of the outcome data collected and analysed by the Worcestershire Learning Disability CAMH Service over a five and a half year period, as an example of a coherent and meaningful approach to its use. The measures used are all part of the core list identified in this project and so the results are directly relevant. The main findings were that:

- the team works with CYP with sufficiently complex needs;
- the team's interventions make a significant, positive difference to:
 - A CYP's mental health/behavioural needs
 - Parental/carer confidence/competence and understanding of their child's needs
 - The impact on the CYP's environment and quality of life
- parents/carers also felt much closer to achieving the specific goals they set initially following intervention; and
- parents/carers were highly satisfied with the service offered and gave specific feedback that helped to shape its development.

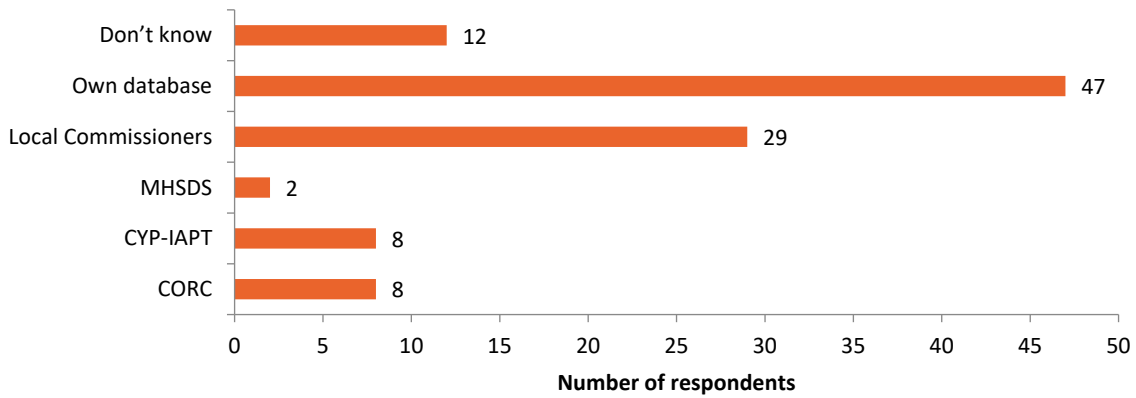
In reality the data was accompanied by a coherent narrative that explained the significance of these findings and how they linked directly to the clinical practice and service specification of the Learning Disability CAMHS.

In the current survey practitioners reported where they submit the outcome data from their service to (Figure 5). It is apparent how few services submit data for CYP with learning disabilities to recognised central collection points such as the Mental Health Services Dataset (MHSDS) and how many hold on to their own data.

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Figure 5: Graph showing where survey respondents submit their service outcome data to (N=95; total responses=106 as participants could choose more than one option).



DISCUSSION AND RECOMMENDATIONS

The primary aim of Stream 1 of this project was to help build further consensus around best practice in the use of formal outcome measures with CYP with learning disabilities and their families. It sought to achieve this by inviting a wide range of practitioners (working in services focusing on the mental health/behavioural needs of these CYP) to take part in a survey. The results of this survey were then compared to those from a previous (less comprehensive) survey and the feedback from two workshops (where the preliminary results were discussed and information on current practice shared). Participants in these workshops reinforced the importance of identifying meaningful and appropriate measures for this group of CYP.

In total 130 practitioners took part in the survey, 95 of these being included in the final analysis. The project managed to include a broad range of practitioners in terms of their profession, the type of service they worked in and the region of the UK in which services were based. This lends some validity to the findings.

In total 49 measures were identified that were in routine use in clinical practice which demonstrates the range of measures necessary to meet the diverse and complex needs of this group of CYP. It is unlikely, therefore, that a prescriptive list of a small number of recommended measures will be sufficient on its own to capture these needs. Instead practitioners will need to be able to draw on a wider toolkit that can be tailored to each individual's specific needs. This toolkit will need to include not only formal measures but also more individualised approaches for CYP with more severe learning disabilities. For this reason, the recommendations in this report cannot be taken in isolation and must be integrated with those from Stream 3 of the project (McElwee and Rossiter, 2021).

Recommended use of outcome measures

The small group of outcome measures that are most widely used with CYP with learning disabilities has remained remarkably stable over the four years since the survey in 2015. The wider group of 11 core measures (of which these are part) were also used more frequently than all of the additional measures identified by participants, reinforcing their importance.

None of the most commonly used measures identified in this project are for 'session by session' use, in contrast to those for CYP without learning disabilities. This, in part, is likely to be the result of change being more gradual for CYP with learning disabilities, meaning that the gap between monitoring points needs to be longer (Rossiter et al., 2014). However the CYP-IAPT/CORC outcome measure toolkit also includes measures to be used every six months or at closure (Law and Wolpert, 2014). The clinical consensus is that this timescale is equally appropriate for CYP with learning disabilities and therefore forms part of the recommendations here.

Table 2 summarises all of the results from the earlier data analyses (age group was not included as all measures are used routinely with 5-17 year olds). The findings from the quantitative and qualitative data in this project lend support to each other allowing some confidence in their validity. Furthermore, these findings are also largely consistent with the quantitative and qualitative data from the 2015 survey. Pulling together all of this information enables an update of the best practice guidance.

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

Table 2: Summary of all analyses of the ‘core’ outcome measures to determine the most appropriate use of each (for details of the analyses see the ‘Findings’ section).

MEASURE (number of respondents in brackets)	LEVEL OF LEARNING DISABILITY ¹ (✓ indicates routinely used with this group, X indicates not)				CLINICAL UTILITY ² (see key at foot of table)				QUALITATIVE ANALYSIS ³ 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

¹ ‘routine use’ is defined as where 50% or more of respondents use a measure with each subgroup

² 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

³ based on whether overall themes/comments indicated this

It is interesting to note that the measures that are rated as having good overall clinical utility are not necessarily those that are in most common use in practice (for example the BPI-01 and Nisonger). Similarly those in common use do not necessarily have good clinical utility (such as the SDQ YP). The GBO is the exception to this, being the most frequently used measure in both 2015 and 2019 surveys and having the best overall clinical utility.

This would seem to indicate the need for outcome measure choice for CYP with learning disabilities to be more evidence driven. The guidance set out below is intended to contribute to this process, giving practitioners some clarity around recommended measures where there is clear supportive evidence from this project. However, practitioners are encouraged to use their clinical judgement, based on the needs of each CYP, to select from the remaining measures where there is less evidence. Further information is also provided as to the potential strengths and weaknesses of each measure to aid their selection and use in clinical practice.

It is important to remember that the recommendations made here are based on practitioners' views on the clinical utility of measures and not on their formal psychometric properties. However, practitioners will have taken these properties into consideration in forming their judgements.

RECOMMENDATIONS

Use of outcome measures with CYP with learning disabilities and their families

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 Outcome 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)

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

These formal measures need to be combined with the project guidance on ‘Hearing the Voice’ in obtaining meaningful feedback directly from CYP with more severe learning disabilities (McElwee, 2021).

Further considerations

For those measures included in the recommendations, the following considerations will assist practitioners with the selection and implementation of them in practice.

1. Universal outcome measures

- **GBO** (measure of impact on agreed goals) – both parents/carers and practitioners are likely to find this a very useful and easy to use collaborative tool. Children and young people, including those with complex learning disabilities, can and should collaborate.
- **CHI-ESQ** (satisfaction with service) – this is not designed as a direct measure of change but may indicate a change in service responsiveness; therefore, it is not for use at the very beginning of a service’s involvement.

2. Measures of impact

- **SLDOM** (measure of impact on parents/carers) – this may not detect change effectively and may feel more useful to practitioners than parents/carers, so its value may need to be discussed; it can be useful for starting conversations about some sensitive issues. Support may be needed with complex language of some items.
- **SDQ Impact** (measure of impact of difficulties on a CYP’s life) – although very easy to complete, it is not clear how useful it is for practitioners and parents/carers, in terms of its ability to capture the more subtle changes in impact on CYP’s lives typically seen in clinical practice.

3. Specific outcome measures

a. For use with CYP with moderate to profound learning disabilities

- **BPI-01** (measure of behaviours; focuses on their frequency and severity) – good overall clinical utility rating.
- **Nisonger** (measure of behaviours; focuses on their frequency and severity) – although sensitive to change, parents/carers may be put off by its length and some of the language used, and may need help to complete it and understand why it is a useful measure.
- **DBC** (measure of behaviours; focuses on clusters of behaviours representing behavioural/emotional issues) – parents/carers may be put off by its length and may need help to complete it and to see its value; there is also financial cost involved.

b. For use with CYP with mild learning disabilities

- **RCADS-P** (measure of mental health symptoms) – although found useful by parents/carers and practitioners this may not detect change in mental health symptoms well and parents/carers may need help to complete it.

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

- **SDQ Parent** (measure of emotional and behavioural factors; broken down into 5 scales) - although in common use and relatively easy for parents/carers to complete, they may not see the value in it given the language may not relate directly to CYP with significant learning disabilities.
- **SDQ YP** (measure of emotional and behavioural factors; broken down into 5 scales) – although in common use, the questions asked may be too complex and abstract for CYP with any significant degree of learning disability to complete, and may therefore not be valued by practitioners, CYP and parents/carers.

4. Additional outcomes measures

- **Appendix 4** shows the range of other measures in use in clinical practice; although there is insufficient data from this survey to draw any conclusions about their clinical utility, practitioners may wish to trial measures that relate to the specific needs of the individual that they are working with.

On the basis of the findings in this project it is not recommended that the CGAS is used with CYP with learning disabilities as an outcome measure.

The ‘participation teams’ that some services have set up with parents/carers may be a useful forum to help share understanding of the value of some of the measures that they may not instinctively feel useful. They may also facilitate the collection of more detailed and direct feedback from parents/carers on the measures used.

It must be stressed again, that these recommendations relate solely to the clinical utility of the measures as assessed by practitioners and the confidence that can be placed in the differences in ratings between them.

The use of outcome measures in practice

Participants in this project highlighted the importance of considering not just which outcome measures to use, but also how they are used. This issue has been brought to the forefront by the COVID-19 pandemic with services employing more remote ways of working. Given the increased rates of poverty and unemployment in families with a CYP with a learning disability (Emerson and Hatton, 2007), there is a risk that ‘digital poverty’ and a lack of space to conduct online meetings confidentially could add additional barriers to accessing services to those that already exist. Some of the measures discussed here (for example the SLDOM) ask about sensitive issues such as whether a parent/carer feels that they are failing in their role. Participants in the workshops felt that it was inappropriate to ask families to complete such measures remotely. Practitioners were also aware of placing an extra burden on families when their resources may already be depleted and stretched. For some families the language used in some of the measures can present as a barrier either because of its complexity or because English may not be their first language. There are some examples emerging, however, where measures are being translated into other languages.

It is unclear how long COVID-19 restrictions will remain in place or which elements of current practice will be retained. It is vital, therefore, in planning for the future that services ensure that CYP with learning disabilities and their families are able to shape the services that they use through accessible and equitable means.

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

It is also important for services to think about the culture around the use of outcome measures. If practitioners do not feel that there is real value in their use or that they are meaningful for the CYP that they work with, then this is likely to affect how (or whether) they present the measures to families. There appears to have been a significant deterioration in the use of outcome measures with this group of CYP and their families over the last few years which may reflect a change in the culture and attitudes within services.

Practitioners feel that the outcome measures available for CYP with learning disabilities and their families are not sufficient to meaningfully capture the full range of their needs (for example the quality of a CYP's life or relationships). To give a fuller and more rounded picture of the changes that families can experience when accessing services, further appropriate measures need to be developed and trialled. However, there are some good examples of the development of measures specifically tailored to the needs of CYP with learning disabilities (for example the Sussex Behaviour Grids; Wedge and Singh, 2014) that deserve further attention.

Data collection

The analysis of the outcome data from the Worcestershire Learning Disability CAMHS team (Appendix 7) demonstrates that the use of some of the outcome measures considered here can produce meaningful information and a coherent narrative that can help shape a service and inform managers and commissioners. It would be helpful if the same level of analysis could be obtained by services submitting data for CYP with learning disabilities centrally.

Currently, very few services are submitting their data to central databases such as the MHSDS. In part this may be due to a fear that it will 'get lost' within the much larger pool of data from CYP without learning disabilities within, for example, CAMH Services. Organisations collecting data need to be able to analyse and report separately on the needs of CYP with learning disabilities in order for practitioners to see the value in submitting it. The system needs to be fit for purpose for all CYP.

In the absence of an appropriate central data collection point there is still value in services sharing anonymised data, to help with benchmarking for services for CYP with learning disabilities. Above all, families need to feel that any feedback they give is valued and has a direct impact on the development of services and practitioners need to be able to give specific examples of this.

Limitations

There are a number of limitations inherent in the methodology of Stream 1 of this project that mean that the findings must be treated with a degree of caution.

Most importantly, it was not possible to gather feedback directly from parents or carers on the outcome measures in use. Although practitioners rated how they thought parents/carers felt, a lack of first-hand information impacts on the validity of the findings. It was never the intention to gather feedback from CYP with learning disabilities in this part of the project.

No formal statistical analyses were performed, so this limits the validity of the reported differences between measures. However, the strict use of 95% confidence intervals to interpret data, along with the fact that the various sources of qualitative and quantitative data reported here (spanning several years) support each other, lends some credibility to the findings. In comparing the quantitative and qualitative data from the

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

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

2015 and 2019 surveys, it is likely that some practitioners participated in both studies which may account to some extent for the similarities found between them. The current survey also included more than one respondent from some services, again potentially impacting on the results (and certainly the demographics). The impact of this is moderated by the fact that practitioners within the same service can have very different views about each outcome measure. Given that respondents came from services working with a wide range of CYP this is likely to have increased the variation within the clinical utility data and reduced the likelihood of finding significant differences between the measures.

Some manipulation of the data helped to simplify and make sense of it, whilst not necessarily being statistically rigorous (for example setting an arbitrary cut-off score of 50/100 for the clinical utility data). Given the benefits for practitioners accessing this guidance this was felt to be an acceptable compromise.

Participants were not provided with definitions of concepts such as 'severe learning disability' and so this was left open to individual interpretation. The aim was to gauge which measures were being used across the spectrum of learning disabilities so it is anticipated that participants will have used these as relative, rather than stand-alone, terms.

Regardless of these limitations, this Stream of the project has produced a rich and coherent series of findings that appear to have good clinical validity. These can be incorporated into updated guidance on the use of outcome measures with CYP with learning disabilities and form a sound basis for further research in this area.

Building on these findings

Future possibilities include obtaining direct feedback from parents/carers on the outcome measures identified here. It would also be beneficial to tap into the local databases that many services are holding in order to bring outcome data together for analysis and benchmarking. Researchers may wish to use the findings here as a starting point for future studies trialling the measures with the specific groups of CYP that they are best suited to, or investigating the potential of the additional measures identified. In addition, the development of measures that are able to capture changes in the more qualitative experiences of families (such as relationships) would add more validity to the feedback gathered. There is a growing body of practitioners who are keen to help this work progress and who can provide valuable support in sustaining its momentum, so it would make sense to harness this enthusiasm going forward.

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