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Division of
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Child Outcomes
Research Consortium

Revised Guidance: Gathering feedback and measuring outcomes and change with children and young People with learning disabilities, their families and networks

October 2021

Rowena Rossiter and Nick Tait on behalf of Project Team

This revised guidance summarises recommendations from the findings of the 2-year project funded by the British Psychological Society's Division of Clinical Psychology and carried out in collaboration with project hosts Child Outcomes Research Consortium (CORC). Project learning used a range of sources and methods (see below*) and builds on [previous guidance](#).

The project's focus is on outcomes and change in mental health and wellbeing and takes a broad, contextual approach, including things that promote mental wellbeing, such as social and community connectedness across services and settings, not just specific 'mental health' services^{1,2,3}.

Whilst this guidance focuses on children and young people with complex learning and communication needs, it is relevant for all children and young people as, "*getting things right for children with complex needs will improve practice with all children*" (Marchant, 2010)⁴.

Please reference this Guidance as:

Rossiter, R. & Tait, N. (2021) Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (CYP-LD), their families and networks: revised Guidance. British Psychological Society Division of Clinical Psychology/Child Outcomes Research Consortium, London.

The content of the guidance represents the findings and views of the project.

Thanks to the project funders, The British Psychological Society's Division of Clinical Psychology, hosts/collaborators, Child Outcomes Research Consortium (CORC) and all who contributed.

Find more information here:

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

FINDINGS

The findings are summarised into **3 main recommendations** and **2 important considerations**:

3 main recommendations	2 important considerations
<ol style="list-style-type: none"> 1. Choose and use outcome measures and methods with clear purpose 2. Set goals that are meaningful 3. Actively seek feedback in a variety of ways 	<ol style="list-style-type: none"> 1. Consider equalities, diversity and inclusion 2. Consider the impact of the pandemic



RECOMMENDATION 1: CHOOSE AND USE OUTCOME MEASURES AND METHODS WITH CLEAR PURPOSE

There is close agreement about what is helpful about using measures and listening to children and young people and their parents/carers from children and young people themselves⁵ and from practice and professional guidance^{6,7,8,9} which have been echoed in this project's finding:

Do	Don't
<ul style="list-style-type: none"> • Familiarise yourself with measures and methods. • Use measures which are appropriate, valid and reliable. • Explain to children and young people and their families and networks what, why and how they will be used. • Provide support to complete them; give feedback and discuss and use the findings. • Follow up with repeat measures. 	<ul style="list-style-type: none"> • Use as a 'tick-box' exercise. • Send out measures for remote completion.

The use of measures can help start conversations and collaboration; learning and listening; personalised approaches and shared decision making; establish baselines and priorities, all of which can contribute to a process of empowerment and 'getting it right'.

They can help with:

- **Goal setting** – 'What is the problem?', 'What do I/we want to change?', 'What do I want?'
- **Relationship building** – 'How are we getting on together?'
- **Measuring change/impact** – 'How are things going?'; 'What has/hasn't changed?', 'What works/doesn't?', 'Have we done as much as we need to?'
- Finding out '**How has the experience been?**' for practice and service development

The key is '*how*' measures and methods are used, not just '*what*' measures and methods are used.

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The recommendations from the project are to use a combination of measures from 1, 2 and 3 below at least every six months, and at closure as measures of outcomes for individual CYP-LD:

NB The strength of evidence base for each measure does vary, full details can be found in the [Stream 1 report](#)¹⁰.

<p>1 Universal outcome & experience measures <i>Use both</i></p> <p>All abilities</p> <ul style="list-style-type: none"> • Goal Based Outcomes (GBO) • Experience of Service Questionnaire (CHI-ESQ/ESQ) 	<p>2 Specific outcomes measures</p> <p>Select at least one from a or b as appropriate:</p> <p>a. CYP with moderate to profound learning disabilities:</p> <ul style="list-style-type: none"> • Behaviour Problems Inventory (BPI-01) • Nisonger Child Behaviour Rating Form (Nisonger) • Developmental Behaviour Checklist (DBC) <p>b. CYP with mild learning disabilities:</p> <ul style="list-style-type: none"> • Revised Children's Anxiety and Depression Scale - Parent Version (RCADS-P) • Strengths and Difficulties Questionnaire - Parent Report (SDQ Parent) and Strengths and Difficulties Questionnaire - Young Person Report (SDQ YP) <p>Use other measures e.g. additional measures for specific needs, across abilities, based on clinical judgement (see Appendix 4 in Phillips, N. & Demjen, E. (2021)).</p>	<p>3 Measures of impact</p> <p>Select at least one:</p> <p>All abilities</p> <ul style="list-style-type: none"> • Sheffield Learning Disability Outcome Measure (SLDOM) • Strength and Difficulties Questionnaire - Impact Supplement only (SDQ Impact)
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For different purposes to individual measures, different approaches are needed. See Appendix 1 for examples of approaches across different levels of impact and service.



RECOMMENDATION 2: SET GOALS THAT ARE MEANINGFUL

Goal Based Outcomes are very useful with children and young people with learning disabilities, their families/carers and others in their network as they are easy to use, flexible and personal. They can be used in and across mental health and wellbeing services, education and participation in other areas.

Key elements in setting goals that are meaningful:

<p>Use key ‘process’ elements (really listen, be interested and open-minded, check for your and their understanding) to set goals that are meaningful including:</p> <ul style="list-style-type: none"> the use of goals to support discussion and negotiation, empowerment and agency; clarifying “what would it look like if it were better/worse?”, “what would be happening when..?” so “fuzzy” concepts such as “agitated”, “anxious”, “aggressive” are expressed in individualised, concrete, measurable, performance terms; focusing on desired goals rather than “problems”. <p>NB The time required for engagement and assessment may be affected by individual need, ensure sufficient time is given.</p>	<p>Use individualised approaches in setting goals that are meaningful:</p> <ul style="list-style-type: none"> be creative to match cognitive and communicative needs e.g. simplified language/concepts, symbols, use of pictures, ladders, card-sort activities or “Talking Mat” type supports, concrete props such as rulers, lengths of string, floor mats, road maps, shaded circles; reduce the numbers in the scale where 0–10 is too great; break-down goals into small, concrete steps to capture smaller changes; plan how and when to collect and collate goal-based information to fit in with key meetings (e.g. Education, Health and Care Plan meetings) to increase motivation and meaningfulness; use photos/videos can be helpful¹¹.
<p>Link with measures and methods to set goals that are meaningful:</p> <ul style="list-style-type: none"> goals that are appropriate for age, abilities and issue which might include emotions/feelings, can be informed by detailed measures of behaviours such as Nisonger, DBC, BPI, parental coping as in The Sussex Behaviour Grids and Additional Measures Table. involve children and young people with learning disabilities directly, including those with complex communication and behavioural needs, by use of methods such as observations, Talking Mats and interviews with parents/caregivers^{12,13}. 	<p>Use different ways to set goals that are meaningful across different domains:</p> <p>Goals for children and young people or parents/carers can relate to:</p> <ul style="list-style-type: none"> objective “behavioural” goals - head banging, throwing toys, time staying in bed, playing with sibling/parent, parent trying new activity, doing mindfulness etc; more subjective feelings related goals - ratings of calmness, anxiety, understanding, coping with individualised behaviour/emotions measures rating different elements such as frequency, duration, intensity, latency and/or different settings such as home, school, shops etc; trying or doing new/different activities, opportunities and strategies for children, young people;

- parents and others understanding of, or confidence about, a child's behaviour, moods or learning needs e.g. *"I now know what to do when X does..."*; *"I feel more confident in parenting my child"* (even when aspects of a child or young person's behaviour or moods may not change), goals may be focused on stabilising and maintaining skills and activities or building in support and fun for families including siblings, especially where there are very complex health or behavioural needs.



RECOMMENDATION 3: ACTIVELY SEEK FEEDBACK IN A VARIETY OF WAYS

Seeking feedback includes:

- hearing, listening to and promoting the 'voice' of children and young people across the full range of learning disabilities, where 'voice' is interpreted as meaning communication, in whichever form works best for the child or young person.
- direct engagement of, and communication with, children and young people, their families and carers, staff and their networks using a range of communication methods and supports for a range of purposes.

Seeking feedback is important at all stages of assessment and formulation, planning, doing and review, in both individual and service contexts. As health and wellbeing are affected by many broad, contextual factors, different settings and foci for 'Hearing the Voice' are included in this project's [Good Practice Examples*](#), their [Thematic Analysis](#), the [Guidelines](#) from them and other consultations and [table of useful organisations and resources](#).

Key elements in gathering feedback effectively:

For this, there needs to be good information that tells people how best to communicate with children and young people with LD and lots of chances for them to communicate; staff/carers/families are good at supporting them with their communication and help them to be involved in making decisions about their care and support, and to understand and communicate about their health (i.e. *The 5 Good Communication Standards*^{14, 15,16}).

This ensures that the environment (physical, social, opportunities, attitudes) and the behaviours, resources and activities of the sender and receiver are aligned to support effective communication. To understand how to better support effective communication with children with complex needs and/or mental health needs (social emotional SEMH) and speech, language and communication needs (SLCN), use resources/training from Triangle¹⁷ or the Royal College of Speech and Language Therapists free online learning tool for staff and parents/carers¹⁸.

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***Good Practice Examples were submitted and selected and analysed on the basis of being developmentally and methodologically sound, innovative, evidence-informed and pursuing key policy/legislative priorities.**

Ways to gather feedback effectively needs the planning and using of personalised communication methods and support which may include:

- direct engagement (verbal and non-verbal)
- observation/structured observation
- finding out from others (family, staff, specialists e.g. psychologists, speech and language therapists)
- communication supports -objects of reference, photos, Photosymbols; Widgit/Communicate in Print, Makaton, videos, VOCA (Voice Output Communication Aids) and other Augmentative & Alternative Communication (AAC) supports.
- Communication frameworks e.g. Talking Mats®, the Mosaic approach¹⁹, Intensive Interaction²⁰

As well as the project materials showing examples, the methods outlined in Gore et al.^{13,14} show how some of the above can be used (see 2 ‘Set goals that are meaningful’) with children and young people with complex needs and behaviours that challenge, and their parents/carers. The CBF ‘Stop, Look, Listen to Me’²¹ and CBF/Mencap Valuing the Views²² also illustrate useful approaches and resources.

For whom, where and how to gather feedback needs consideration of the focus, level of impact, ages, ability and settings including:

- individually (e.g. [advocacy/self-advocacy](#); for complex and sensitive issues e.g. [intimate care](#) and use of [restrictive practice/restraint](#))
- in groups (focus groups-belonging in school, [service improvement](#) and [participation groups](#))
- with children and parents (e.g. [co-produced and co-run approach to staff selection](#))
- across ages
- across abilities
- in schools, community services and settings, residential schools and homes, legal processes.

Two of the Good Practice Examples ([Example 1](#) & [Example 2](#)) hear about the COVID related experiences of children and young people with learning disabilities and highlight the range of ways individuals have experienced restrictions.

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Use key ‘process’ elements (really listen, being interested and open minded, checks for your and their understanding) to gather feedback effectively including:

- use of routine, structure, choice (needs weaving into daily life), in addition to communication scaffolds and supports as multi-sensory resources and activities;
- promote engagement and rapport through interactions which are warm and meaningful not purely functional;
- listen and check out ‘You told me?’, ‘This or that or something else?’ if child uses language, and/or ‘non-judgemental’ observational commentary;
- knowing how/enabling children to say ‘No’, ‘I don’t understand’ and their indicators that they may be in pain, discomfort or distress.

These processes link to use of the stages of ‘The 3 R’s i.e. [Regulate, Relate and Reason](#)’.

Think about issues in gathering feedback from parents/carers and others in child’s network which may also influence the process including:

- adults can have learning needs themselves, experiences of trauma, English not as a first language etc, which can impact on communication, so communication supports may be needed;
- The 3 R’s i.e. Regulate, Relate and Reason applies to adults (parents/carers, practitioners, ourselves), as well as children and young people ([Hearing the Voice Guidelines](#));
- Evidence-based frameworks and training such as the [Solihull Approach](#)²³, [Family Partnership Model](#)²⁴, [Scotland Trauma Informed Approaches](#)²⁵, [LD Professional Senate Top Tips](#)²⁶ or [Power Threat Meaning Framework](#)²⁷ may assist;
- Remember, some have experienced significant change, loss and trauma through the pandemic and some have found additional coping skills.

Things that help- look out for these and use:

- people and organisations that value, model and support gathering feedback/listening and use the feedback;
- people and organisations that see this as ‘investment’ not ‘asking extra’;
- opportunities to collaborate to gather feedback builds energy, interest, skills and agency in children and young people, staff and parents/carers;
- ways to link outcomes, goals and feedback to what children and young people want, their parents or carers and school/other settings and collect information and views across settings (i.e. ‘triangulate’)²⁸;
- remember, policy and legislation require us to do this.

Things that can get in the way (barriers) watch out for these things, prioritise and problem-solve with supportive colleagues as appropriate.

- practical, technical and attitudinal issues – whilst these are different and need different approaches, they can present in the same way e.g. ‘haven’t got time/resources’, ‘X can’t communicate’ can be based on practical, technical and/or attitudinal factors which need exploring/unpick;
- the challenges of deciding ‘whose view?’ where children, young people, parents, staff views of views may differ; views may be ‘filtered’ by others which may impact on the validity of the view or ‘voice’. This can be important to explore/unpick;
- Covid related issues e.g. PPE, changes in routines, activities, contact with families/staff.



OTHER CONSIDERATIONS

Consider equalities, diversity and inclusion

We need to ensure we really listen to all children and young people with LD and their families and carers, with open and curious minds and pre-judgements suspended. The project recognises the need for more focus and action on racism and all protected characteristics including age, ability/disability, gender, sexuality, etc and their intersectionalities. The groupings or labels (diagnoses, ‘protected characteristics’ etc) that may be attached to a child, young person with LD, their family or carer tells us little about their personal lives, likes/dislikes, talents and needs. *Tools for Talking* resources co-developed with people with LD to facilitate culturally sensitive, person-centred communication and understanding, service planning and delivery²⁹ can assist.

We also need to consider practicalities such as [language](#) used in measures and availability of translations, as well as the appropriateness of Western or Eurocentric models and measures of mental health.

Difference and intercultural presence of race, class, gender, sexuality, age and ability issues can evoke feelings and dynamics of power, fear, uncertainty, shame etc, that we may be unaware of.

We need to uncover assumptions, unconscious biases and issues around stigma, discrimination and privilege in ourselves and the services we work in, and find space and ways to think, plan and behave differently.

Consider the impact of the pandemic

As it is too early to have identified long term impacts and ways of mitigating these, guidance is limited. Project consultations with children and young people, families and practitioners show what they find helpful in getting through the pandemic:

- Involving groups of children and young people with LD, e.g. in a school or residential college, and families to consider ‘*How are they feeling about coming back to school?*’; ‘*What are they worried about?*’ and ‘*What would help with worry?*’. This will show the range of responses, enable identification of possibilities for support, goals and measures, and engage and empower them.
- Learning from changes in work practices, e.g. more working virtually, using outcome measures digitally to innovate, improve access, with implications on measuring ‘*what*’ and ‘*how*’³⁰.
- Recognising and planning to reduce the differential impact of the pandemic on health and social inequalities across differing groups^{31, 32}.

APPENDIX 1

Recommendation 1 Choose and use outcome measures and methods with clear purpose Examples

[Sussex NHS Partnership Trust's Family Intensive Support Service/CAMHS-LD approach](#) to measuring change and outcomes with the suite of measures used (what, when and how).

For different purposes to individual measures, different approaches are needed. Examples of approaches across different levels of impact and service:

- For *evaluating psychological wellbeing and change* within settings or services (schools, short breaks service), [measures of School Belonging and Connectedness were used](#); the [Participation and Engagement Audit Tool](#) from the Council for Disabled Children.
- *For monitoring wellbeing*, as a screen or assessment of broad needs at a population level, the SDQ Parent Report was found to perform satisfactorily in analysis of data comparing children and young people with, and without LD with the same SDQ cut-off for 'caseness' (strong association between the SDQ Total Difficulties score and the DBC16). However, for measuring outcomes and change for 'clinical' referrals, whilst the SDQ may measure change with children and young people with milder learning disabilities, it is not sufficiently sensitive to measure change for those with more substantial learning needs.
- **For evaluating outcomes and change at service levels:**
 - individual measures can be aggregated over time and shared with Commissioners as in [Worcestershire Learning Disability CAMHS](#);
 - integrated approaches with individual and family measures and other performance measures, such as length of stay on in-patient unit such as in [Northumberland, Tyne & Wear NHS Foundation Trust's integrated approach](#) to measuring outcome in an innovative inpatient CYP-LD service;
 - 0-25 Multi-agency SEND Data Dashboard -a commissioning tool to support local areas to understand their data on need (Local profile); 'what did we do and how well are we doing?' (Governance and assurance) and 'how do we know we are making a difference?' (Key Performance Indicators) using data already captured, developed by [Council for Disabled Children](#).

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REFERENCES

*Project sources and methods included consultations (over 110 people across 20 organizations; children and young people with LD and some other neurodevelopmental conditions, parents and carers, practitioners, managers and commissioners (see 'Project Team & Funders'), detailed survey of measures and methods, interrogation of data in the UK Millenium Cohort Study, reviewing literature, seeking and analysing examples of good practice initiatives for gathering feedback/'Hearing the Voice', workshop and webinar discussions, [across a range of levels](#) to find out what works well, what barriers there are and implications. All overseen, considered and synthesised by the Project Management Group.

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⁴Marchant, R. (2010). Making Assessment Work with Children with Complex Needs. In J.Howard (ed) *The Child's World: The Comprehensive Guide to Assessing Children in Need*. 2nd Ed. (pp 199-213). London: Jessica Kingsley.

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¹¹Council for Disabled Children (2021). *Top Tips for professionals who support children and young people to participate in their Education, Health and Care plan* <https://councilfordisabledchildren.org.uk/sites/default/files/uploads/attachments/web.Top%20Tips..pdf>

¹²Gore, N. J., McGill, P., & Hastings, R. P. (2019). Making it meaningful: caregiver goal selection in positive behavioral support. *Journal of Child and Family Studies*, 28, 1703–1712. <https://doi.org/10.1007/s10826-019-01398-5>.

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- ¹⁵Royal College of Speech and Language Therapists. (2019). *Supporting children and young people with SEMH: the five good communication standards*. [Supporting-children-A4 No Marks.pdf \(rcslt.org\)](#)
- ¹⁶Royal College of Speech and Language Therapists. (2019). *Supporting children and young people in care: the five good communication standards*. [5-good-standards-a4-2019.pdf \(rcslt.org\)](#)
- ¹⁷Triangle
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- ²³The Solihull Approach [About Us - Solihull Approach | Parenting \(solihullapproachparenting.com\)](#)
- ²⁴Family Partnership Model [Family Partnership Model \(FPM\) \(slam.nhs.uk\)](#)
- ²⁵NHS Education for Scotland Trauma Informed Practice resources <https://www.nes.scot.nhs.uk/our-work/trauma-national-trauma-training-programme/> and video <https://vimeo.com/274703693>
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