Measuring outcomes and change

Table signposting

1) **Additional information/links to measures/methods for measuring outcomes and change for children and young people with profound, multiple and complex learning disabilities**

2) **Examples of approaches to service outcome measurement**

(from project consultations, literature reviews, networking and workshops

Individual focus		
Measure/method -title & author(s)	**Focus:**	**Can be found at:**
Collection: **Assessment measures available for practitioners and researchers. Revised version (V2)** 2021 From: FIND (Further Inform Neurogenetic Disorders) & Cerebra Centre for Neurodevelopmental Disorders	14 observational & informant-based assessments focusing on various domains of behaviour and emotion for clinical and research use; majority are designed for use with people with profound to moderate intellectual disability, are sensitive to context and compromised self-report. See also Oliver, C., Royston, R. & Crawford, H. (2021) *Informant assessments of behaviour and affect for people with intellectual disability.* Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham.	Free Download (register to access) https://www.findresources.co.uk/professionals/login Includes Challenging Behaviour Questionnaire (CBQ); Mood, Interest and Pleasure Questionnaire (MIPQ); Be-Well checklist; Repetitive Behaviour Questionnaire (RBQ); The Activity Questionnaire (TAQ) Translations for some measures in some languages
Engagement Profile (Carpenter, B.)	Collect & record engagement data (eg photo, video) in a framework with comments, context, indicators across	The Engagement Model – Barry Carpenter Education

Find more information here:
https://www.corc.uk.net/outcome-experience-measures/feedback-and-outcome-measures-for-children-and-young-people-with-learning-disabilities/

	domains of Anticipation, Curiosity, Discovery, Initiation Investigation, Persistence, Responsiveness. Overview of learning outcomes with evidence (formative and summative assessment), overtime/ different levels, detailed observation & recordings; Assessment book overview, video, tracking; Engagement Reports –data and evidence. App available.	www.**evidenceforlearning**.net alan.wood@theteachercloud.net
Nick Gore & Peter McGill, Peter *Making it Meaningful: Caregiver Goal Selection in Positive Behavioral Support.* Nick Gore, Peter McGill & Richard Hastings *Personalized Goals for Positive Behavioral Support: Engaging Directly*	Use of Talking Mats & semi-structured interviews to support caregivers of children with IDD who displayed behaviours that challenge, to develop goals for Positive Behavioural Support. Focused on quality of life for caregivers & child, adaptive & challenging aspects of child behavior & aspects of caregiver's own behavior. Develop & demonstrate a means of engaging directly with children to identify personalized goals and priorities for their future support. Talking Mats	Gore, Nick J. and McGill, Peter (2019) Making it Meaningful: Caregiver Goal Selection in Positive Behavioral Support. *Journal of Child and Family Studies*, online. pp. 1-10. ISSN 1062-1024. Gore, N.J., McGill, P. & Hastings, R.P. (2021) Personalized Goals for Positive Behavioral Support: Engaging Directly with Children who have Intellectual and Developmental Disabilities. *Journal of Child and Family Studies* https://doi.org/10.1007/s10826-020-01867-2 Open access - https://rdcu.be/cc8ec

with Children who have Intellectual and Developmental Disabilities.	communication approach facilitated interviews with children who had a range of disabilities & displayed behavior that challenges about activities, their own behavior, a caregiver's behavior, and quality of life to focus future potential assessment and intervention.	
McGreevy, P. & Fry, T. *Essential for Living: A Communication, Behavior & Functional Skills Curriculum, Assessment, Skill-tracking Instrument, & Professional Practitioner's Handbook for Children & Adults with Moderate-to-Severe Disabilities*	Domains- How Children and Adults Interact with the World Around Them; Speaking and Listening; Doing; Tolerating; Inappropriate Behavior; Tool Movements. Skills are sequenced from less to more difficult; more to less functional, and designated as: *must-have (the Essential Eight), should-have, good-to-have & nice-to-have.*	EFL-Intro-UserGuideNewFinalDigital2 (essentialforliving.com)
Oliver et al. *Be Well Checklist*	Checklist for carers and professionals to consider factors which may affect behaviour and wellbeing of CYP-LD eg pain, discomfort, sensory sensitivity, anxiety, poor sleep, emotional control, impulsivity, insistence on sameness	Oliver et al. (2020). The behaviour and wellbeing of children and adults with severe intellectual disability and complex needs: The Be-Well checklist for carers and professionals. *Journal of Paediatrics and Child Health,* 30; 12.
Distress Assessment Tool (DisDAT)	Tool to observe & document signs and behaviours of distress and when an individual is content	Regnard et al. (2007) Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool

		(DisDAT). J Intellect Disabil Res; 51(Pt 4):277-92. doi: 10.1111/j.1365-2788.2006.00875.x Available at Disability (stoswaldsuk.org)
Horridge, K. (2018) *Children with Disabilities Terminology Set (DTS)* and traffic light tool	Case Study describing development and use of Horridge's tool for identifying, prioritising and reviewing needs in Children with Disabilities(NHS Digital).	https://councilfordisabledchildren.org.uk/sites/default/files/uploads/files/SNOMED-CT%20Case%20Study%20-%20Sunderland.pdf
Service focus		
Measure/method or good practice example-title and author(s)	**Focus:**	**Can be found at:**
Copy of Appendix 7 Evaluation of the effectiveness of the Worcestershire Learning Disability CAMHS Team	Example of analysis, collation and reporting of service measures over 5+ years (for managers and commissioners)	https://www.corc.uk.net/media/2863/good-practice-example-evaluation-of-the-effectiveness-of-the-worcestershire-learning-disability-camhs-team-analysis-of-55-years-worth-of-outcome-data.pdf
Northumberland, Tyne & Wear NHS Foundation Trust: poster	Example of integrated approach to measuring outcome in innovative inpatient CYP-LD service	https://www.corc.uk.net/media/2844/eval-intensive-pbs-ross-burdiss-legg.pdf
Sussex Partnership Foundation NHS Trust Family Intensive Support Service/CAMHS-LD approach to measuring change and outcomes	Good Practice example of a suite of measures in a service– what, when and how they are used	https://www.corc.uk.net/media/2845/2017-08-30-sussex-behaviour-grids-final-version-pdf.pdf https://www.corc.uk.net/media/2846/2017-08-30-sussex-behaviour-grids-follow-up-final-version-pdf.pdf

Find more information here:
https://www.corc.uk.net/outcome-experience-measures/feedback-and-outcome-measures-for-children-and-young-people-with-learning-disabilities/