APPENDICES: 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)

June 2021

Dr Neil Phillips
Lead Stream 1/Clinical Psychologist
(Herefordshire and Worcestershire Health and Care NHS Trust)

Eniko Demjen
Assistant Psychologist
(Herefordshire and Worcestershire Health and Care NHS Trust)

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

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

APPENDIX 1

Outcome measure survey (June 2019)

Outcome Measures for Children and Young People with Learning Disabilities and Their Families

About this survey

Who is this survey for?

This survey is aimed at all professionals working with children and young people with learning disabilities who focus on mental health/behavioural issues.

This includes professionals in:

- Learning Disability CAMHS Teams
- Intensive Support Services
- Psychology/Behavioural Services
- Positive Behaviour Support Services
- Lifespan Learning Disability Services
- Educational settings
- Private practice
- Community Learning Disability Services for children and young people, and
- Mainstream Services (e.g. CAMHS, Paediatrics).

Why complete this survey?

Currently there is no clear consensus about the best ways to gain meaningful feedback from children and young people with learning disabilities and their families about the services we provide. This survey is part of a wider two year project funded by the British Psychological Society that is looking to address this. It builds on a previous project completed in 2015.

We really need your help to build up a clear picture of which outcome measures services are using across the UK and how useful you and families find these. The findings will form part of national guidance which we will publish in 2020.

We are keen to include children and young people with a wide range of abilities including those with more profound and multiple disabilities.

How to do it

We have listed some of the most popular measures from our previous project as well as a 2018 CORC survey. We have also left room for you to add your own as well. You only need to answer further questions for those measures that you use routinely.

We really appreciate you taking the time to do this. The more responses we can collect the more meaningful the results will be.

The survey should take no longer than 15-20 minutes to complete.

Appendix 1 (cont.)

About you

1. **Which of the following best describes you? (you can select more than one):**

Nurse
Psychiatrist
Social Worker
Psychologist
Therapist
Counsellor
Commissioner
Service manager
Other (please specify)

2. **Which best describes the service for children and young people that you work in? (you can select more than one):**

Learning Disability CAMHS
Intensive Support Services
Psychology/Behaviour Support Service
Positive Behaviour Support Service
Lifespan Learning Disability Service
Community Learning Disability Service
'Mainstream' Service
Other (please specify)

3. **Which of the following best describes the sector of the service? (you can select more than one):**

NHS
Voluntary sector (e.g. charity)
School, college or educational setting
Youth Justice
Local authority
Independent (private)
Other (please specify)

4. **Where is the service in the UK?**

Greater London
South East
South West
West Midlands
North West
North East
Yorkshire and the Humber
East Midlands
East of England

Scotland

Wales

Northern Ireland

Other (please specify)

<u>The outcome measures you use</u>

We are now going to ask you about the below outcome measures. If you say that you use any of them a few further questions will appear.

There is also space for you to add up to 5 additional measures that you use.

Measures of symptoms/functioning

DBC (Developmental Behaviour Checklist)

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

SDQ Parent (Strengths and Difficulties Questionnaire) - Parent Report

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

Nisonger (Nisonger Child Behaviour Rating Form (Parent)

CGAS (Children's Global Assessment Scale)

BPI-01 (Behavior Problems Inventory)

Measures of Impact

GBO (Goal Based Outcomes)

SDQ Impact (Strength and Difficulties Questionnaire) - impact supplement only (ie page 2)

SLDOM (Sheffield Learning Disability Outcome Measure)

Evaluation of Service

CHI-ESQ/ESQ (Experience of Service Questionnaire)

Appendix 1 (cont.)

The outcome measures you use (cont.)
For each listed/additional measure used the following additional questions appear:

1. **I typically use this measure with children and young people whose learning disability is described as (you can select more than one):**

mild
moderate
severe
profound
don't know

2. **I typically use this with children and young people who are aged (you can select more than one):**

0-4 years
5-11 years
12-17 years
18-25 years
don't know

3. **How useful do you find it (0-100)?**

not useful at all   neutral   extremely useful

     0   100

4. **How useful do you think parents/carers find it (0-100)?**

not useful at all   neutral   extremely useful

     0   100

5. **How easy do you think parents/carers find it to complete (0-100)?**

extremely difficult   neutral   extremely easy

     0   100

6. **How well do you think it detects change (0-100)?**

not at all   neutral   extremely well

     0   100

7. **Pros and cons of the measure?**

pros:
cons:

8. **Any other comments?**

Appendix 1 (cont.)

The data you collect

1. **Where does the outcome data that you collect go to?** (you can select more than one)

CORC (Child Outcomes Research Consortium)
CYP-IAPT (Children and Young People's Improving Access to Psychological Therapies)
MHSDS (Mental Health Services Dataset)
Local commissioners
Saved on your own database
Don't know
Other (please specify)

2. **How do you use the data you collect from your outcome measures?**

3. **We have found that a lot of the data from services for children and young people with learning disabilities is not being gathered centrally.** Would you be willing to share anonymised data (with sufficient safeguards in place) to enable this to happen and to allow analysis and benchmarking? (none of the information you provide here will be used for this purpose without your explicit consent later and you are free to change your mind at any time)

Yes
No
Maybe

The views of people who use your service

1. **Do you gather any feedback from children and young people/parents/carers about the outcome measures that you use?**
Yes
No
Don't know

2. **Do you have links to any groups who might be willing to give feedback?**
Yes
No
Don't know

3. **If so would you be willing to gather this information?**
Yes
No
Maybe

Appendices: 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)

Appendix 1 (cont.)

The service that you work in

We would be grateful if you could tell us the name of the service that you work in. This information will be used solely to group together responses from the same service so we are able to tell for example how many services (rather than individuals) use a particular measure. You may skip this question however if you do not want to share this.

1. **What is the name of the service you work in?**

Thank you very much for completing this survey.

If you have any queries or would like your name to be added to our circulation list about the project and its next stages, can you please email both of us:
neilphillips@nhs.net; eniko.demjen@nhs.net

Neil Phillips (Clinical Psychologist)
Eniko Demjen (Assistant Psychologist)
Herefordshire and Worcestershire Health and Care NHS Trust
June 2019

APPENDIX 2

Initial email invitation to complete survey (sent 27/06/19)

Hi everyone,

You may be aware that at the start of the year a group of us secured funding from the BPS to complete a 2 year project in conjunction with the Child Outcomes Research Consortium (CORC). The focus is on how to gain meaningful feedback from children and young people with learning disabilities and their families about the services they receive as there is no clear consensus nationally as to the best ways to do this.

Part of the project is to build up a picture of which outcome measures are being used across the UK in services focusing on mental health/behavioural issues and how useful families and services find these. As professionals working in this area therefore we would be very grateful if you could complete our online survey (which builds on a previous survey from 2015). The findings will inform national guidance which we will publish in 2020.

The survey can be completed through one of the links below (and should take no more than 15-20 minutes). The deadline for completion is the end of Friday 19th July 2019.

We would also appreciate you sharing this email with as many colleagues in your own service and in other services (whatever profession) as you can. The more responses we can generate the more meaningful the results.

Link to the CORC website for more information and the survey: https://www.corc.uk.net/news-blog/corc-collaborates-in-project-to-grow-best-practice-in-using-outcome-measures-in-cyp-with-learning-difficulties/

Direct link to the survey: https://www.surveymonkey.co.uk/r/MYQDZFH

We are sending the survey out from a number of sources so apologies if you receive it more than once. If you have any queries please feel free to email (copying us both in).

neilphillips@nhs.net; eniko.demjen@nhs.net

Best wishes and thanks for your help
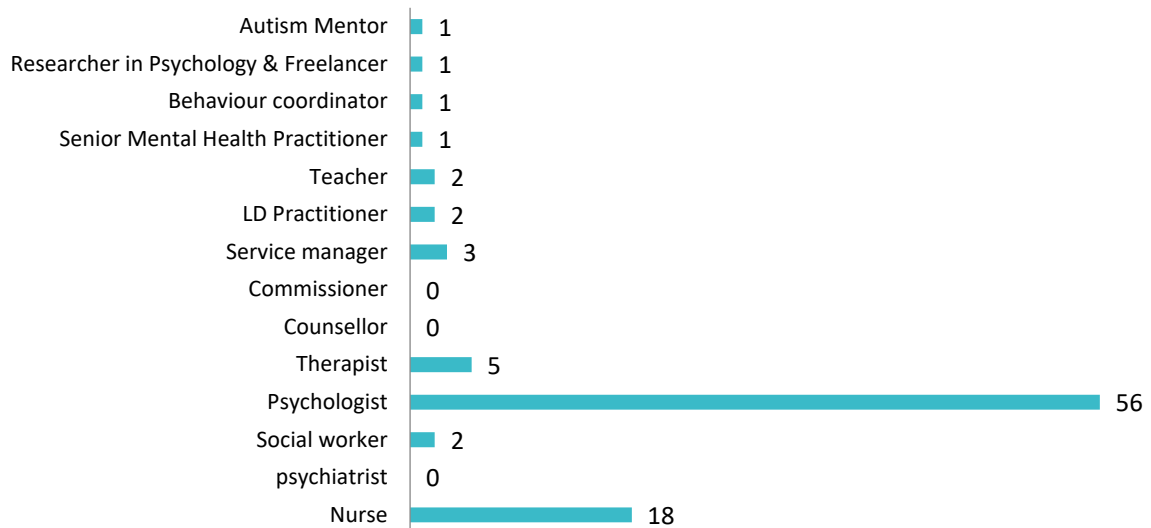

Neil Phillips (Clinical Psychologist)

Eniko Demjen (Assistant Psychologist)

Herefordshire and Worcestershire Health and Care NHS Trust

Appendices: 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)

APPENDIX 3

Demographic data from survey respondents (N=95)

Figure A: Profession of survey respondents

Profession	Count
Autism Mentor	1
Researcher in Psychology & Freelancer	1
Behaviour coordinator	1
Senior Mental Health Practitioner	1
Teacher	2
LD Practitioner	2
Service manager	3
Commissioner	0
Counsellor	0
Therapist	5
Psychologist	56
Social worker	2
psychiatrist	0
Nurse	18

Figure B: Service that respondents work in

Service	Count
Mainstream Service	8
Community LD Service	12
Lifespan LD Service	4
Positive Behaviour Support Service	4
Psychology/Behaviour Support Service	6
Intensive Support Services	4
LD CAMHS	43
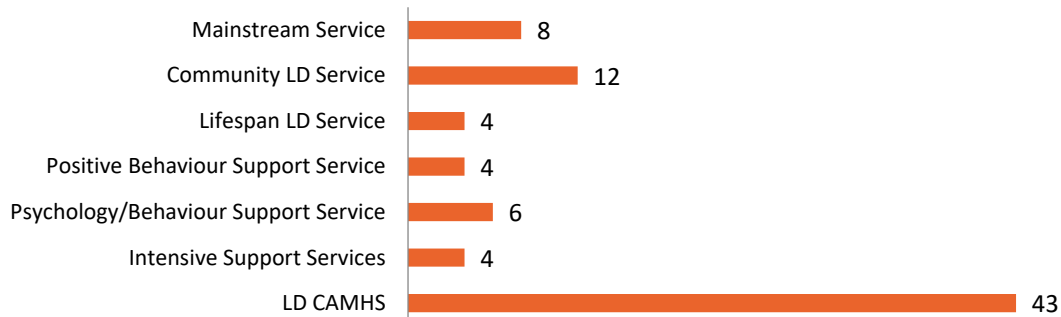
Figure C: Sector service lies within
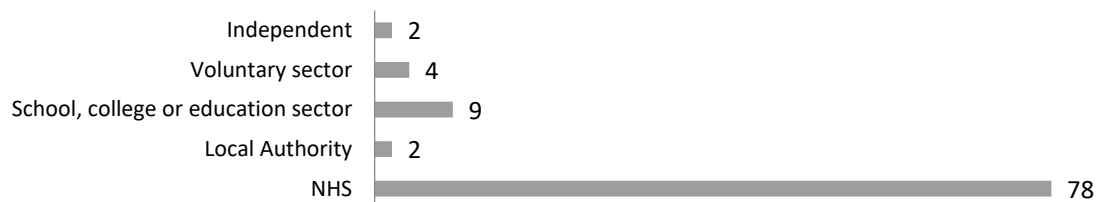
Sector	Count
Independent	2
Voluntary sector	4
School, college or education sector	9
Local Authority	2
NHS	78

Appendices: 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)

Appendix 3 (cont.)

Figure D: Country/region of UK service is based in

APPENDIX 4

Quantitative and qualitative data from the 38 additional measures in use routinely by survey participants (data not shown for those measures where N=1)
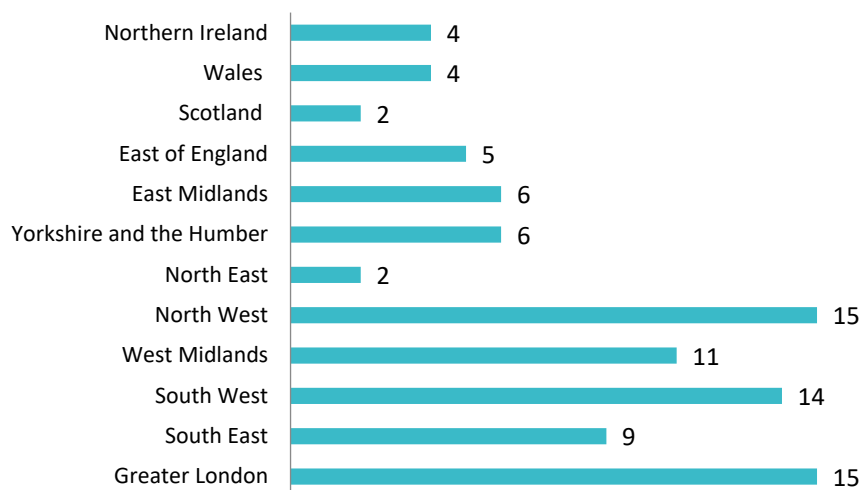*(References are given at end of this Appendix, where available, indicated by a numerical superscript attached to the measure's name)*

Measure	No of respondents (N)	Typical use (% of respondents using each measure with specific sub-groups)		Clinical utility (average score out of 100 where 100 is the most positive)				Pros	Cons
		Level of learning disability	Age group (years)	How useful: clinician	How useful: parent/ carer	How easy to complete	How well detects change		
MEASURES WHERE N>1									
Mood measures									
Glasgow Anxiety and Depression Scale[1]	5	Mild (100%) Moderate (50%)	5-11y (25%) 12-17y (75%) 18-25y (50%)	80	75.5	78	75.5	Adapted for CYP with learning disabilities , some validation data, accessible, easy to use/understand	Can be long – reluctant to fill in, some questions can be misinterpreted (physical symptoms). Suitable for older and for those with more abilities
Process measures									
Session Feedback Questionnaire ('How was this meeting'?) [2]	2	Moderate-severe 100%	5-17y 100%	72.5	42.5	97.5	25	Indicates we are open to feedback; Helps reflect on how helpful our consultations are to the network	Subjective, dependent on relationship,
Session Rating Scale (SRS)[3]	2	Mild-moderate 100%	5-17y 100%	37.5	22	36	38	Feedback on session	Difficult, limited validity

Appendices: 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)

Appendix 4 (cont.)

Measure	No of respo-ndents (N)	Typical use (% of respondents using each measure with specific sub-groups)		Clinical utility (average score out of 100 where 100 is the most positive)				Pros	Cons
		Level of learning disability	Age group (years)	How useful: clinician	How useful: parent/ carer	How easy to complete	How well detects change		
Parents/adult measures									
Brief Parental Self-Efficacy Scale[4]	3	Moderate and severe 100% Profound 66%	5-17y 100%	67.7	63	82.3	71.3	Quick and easy; brief and focussed	Language not very sensitive; similar to Sheffield LD Outcome Measure (SLDOM)
Behaviour measures									
BBAT Brief Behavioural Assessment Tool[5]	3	Mild, moderate, severe 100%	18-25y 100%	68	60	73.5	69	Thorough	Can take a while to complete
Sussex Behaviour Grids[6]	2	Moderate-severe 100%	0-17y 100%	80	59.5	74.5	88.5	Simple language, tick box, succinct, wide range of behaviours, parental confidence	Making sure parents do fill it in
Goal based measures									
Child Outcome Rating Scale/ Outcome Rating Scale (CORS/ORS)[7]	2	Mild, moderate, severe 100%	0-4 50% 5-11y &12-17y 100%	44	52.5	53	50	Measures impact, designed for younger children, we use it creatively	Not validated; difficult for child to fill out

Appendix 4 (cont.)

Measure	No of respo-ndents (N)	Typical use (% of respondents using each measure with specific sub-groups)		Clinical utility (average score out of 100 where 100 is the most positive)				Pros	Cons
		Level of learning disability	Age group (years)	How useful: clinician	How useful: parent/carer	How easy to complete	How well detects change		
Other									
CORE LD[8]	2	*scattered data*	18-25y 100%	67.5	65.5	71.5	56.5	Mixture of words and images. tracks changes fairly user friendly	No clinical thresholds , only a 3 point rating scale
Gloucestershire LD outcome measure	2	Severe 100%	5-17y 100%	69	76.5	81.5	59	Easy to complete; incorporates CHI-ESQ	In pilot stage currently
Guernsey Community Participation and Leisure Assessment[9]	2	Moderate-severe 100%	*scattered data*	88.5	74.5	72.5	89.5	Outcome focused, broad, sensitive thinks about quality of life	Adult focused, wording a bit old
HONOS – LD/HONOSCA[10]	3	Mild, moderate, severe 100% Profound 66%	5-11y &12-17y 33% 18-25y 66%	65	16	40	70	Holistic, tracks change well, brief	Not client friendly, isn't a self-report measure, measures aspects of disability that are unlikely to change from CAMHS intervention e.g. self-care skills
The Therapy Outcome Measure (TOM)[11]	2	Mild, moderate, severe 100%	5-25y 100%	63	24.5	27	55	Activity and participation section captures positives changes	Subjective to the therapist's view, not person centred

Appendices: 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)

Appendix 4 (cont.)

Mood measures
Emotional Literacy Checklists[12]
Paediatric Index of Emotional Distress (PIED)[13] (accessible widget version)
Psychological Therapies Outcome Scale-ID [14]
Rosenberg Self Esteem Scale[15] (accessible widget version)
Spence Anxiety Scale[16] (accessible widget version)
Wellbeing award for schools pupil evaluation[17]
Health measures
Glasgow Epilepsy Outcome Scale (GEOS)[18]
Process measures
Acceptance
Alliance measure (from Family Partnership Model; Davis, H.)
Parent/adult measures
Challenging Behaviour Attributions Scale (CHABA)[19]
A measure taken from Dyadic Developmental Psychotherapy (DDP; Hughes, D.), Therapeutic Parenting Group workbook- 'How well do you care for yourself' used with parents
Stress and burnout for parents

Appendices: 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)

Appendix 4 (cont.)

Organisational measures
PBS academy organisation checklist[20]
Behaviour measures
Individual Behaviour Rating Scale Tool (IBRST)[21]
Adaptive behaviour measures
Vineland[22]
Goal based measures
I use a *simple goal based measure* adapted from CORC to clarify what families want from the service and how near they are to that goal at each point when the measure is reviewed. They are also asked to rate how concerned/worried they feel re the issue that brings them to the service
Home-made measure where I have combined *Goal Attainment Scaling* (GAS)[29] goals & the *Canadian Occupational Performance Measure[30]*
Other measures
Adolescent Sexual Knowledge and Attitudes (ASKA)[23]
Bild Sexual Health Capacity Assessment [24]
Behaviour Problem Inventory Short form (BPI-S)[25]
Child Friendly Questionnaire (Made by own team)
Mini-MANs-LD Quality of Life[26] (based on Maslow hierarchy)

Division of Clinical Psychology

the british psychological society

CORC Child Outcomes Research Consortium

Appendices: 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)

Appendix 4 (cont.)

PEDIC[31]
Pre and Post Sexual Health Assessment
Ridgeway outcomes measure (burden of treatment)[27]
Target Monitoring and Evaluation (Dunsmuir)[28]

References (where available):

1. Mindham, J., and Espie, C. (2003). Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research, 47*(1), 22-30.

2. Session Feedback Questionnaire (SFQ). Available at: https://www.corc.uk.net/media/1405/sfq_questionnaire.pdf

3. a. Campbell, A. and Hemsley, S. (2009). Outcome Rating Scale and Session Rating Scale in psychological practice: Clinical utility of ultra-brief measures. *Clinical Psychologist*, 12, 1–9.

   b. Duncan, B., Miller, S., Sparks, J., Claud, D., Reynolds, L., Brown, J. and Johnson, L. (2003). The Session Rating Scale: Preliminary psychometric properties of a "working" alliance measure. *Journal of Brief Therapy*, *3*(1), 3–12.

4. Brief Parental Self-Efficacy Scale. Available at: https://www.corc.uk.net/media/1279/brief-parental-self-efficacy-scale.pdf

5. Smith, M. and Nethell, G. (2014). The Brief Behavioural Assessment Tool – preliminary findings on reliability and validity. *International Journal of Positive Behavioural Support*, 4(2), 32-40.

6. Wedge, S. and Singh, R. (2014). *Sussex Behavior Grids.* Sussex: Sussex Partnership NHS Foundation Trust.

7. Miller, S., Duncan, B., Brown, J., Sparks, J., and Claud, D. (2003). The Outcome Rating Scale: A preliminary study of the reliability, validity, and feasibility of a brief visual analogue measure. *Journal of Brief Therapy*, 2, 91-100.

Appendices: 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)

Appendix 4 (cont.)

8. Barrowcliff, A., Oathamshaw, S. and Evans, C. (2018). Psychometric properties of the Clinical Outcome Routine Evaluation-Learning Disabilities 30-Item (CORE-LD30). *Journal of Intellectual Disabilities Research,* 62(11), 962-973. Available at: https://www.corc.uk.net/outcome-experience-measures/core-measurement-tools/

9. a. Baker, P. (2000) Measurement of community participation and use of leisure by service users with intellectual disabilities: The Guernsey community participation and leisure assessment (GCPLA). *Journal of Applied Research in Intellectual Disabilities*, 13, 169-195.

    b. Baker, P., Taylor-Roberts, L. and Jones, F. (2020). Development of the Guernsey community participation and leisure assessment—Revised (GCPLA-R*).*

    Journal of Applied Research in Intellectual Disabilities, 34, 218– 228.

10. Roy, A., Matthews, H., Clifford, P., Fowler, V., and Martin, D. (2018). Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS–LD). *British Journal of Psychiatry,* 180(1), 61 – 66.

11. John, A., Hughes, A. and Enderby, P. (2002). Establishing clinician reliability using the therapy outcome measure for the purpose of benchmarking services. *Advances in Speech Language Pathology*, 4(2), 79-87.

12. Faupel, A. (2003). *Emotional literacy: assessment and intervention: ages 7 to 11.* London: NferNelson.

13. O'Connor, S., Ferguson, E., Carney, T. , House, E. and O'Connor, R. (2016). The development and evaluation of the paediatric index of emotional distress (PI-ED). *Social Psychiatry and Psychiatric Epidemiology*, 51, 15–26. *(Accessible widget version -contact gemma.slack@thepsychologytree.com with evidence the PIED manual and forms have been purchased)*

14. Vlissides, N., Beail, N., Jackson, T., Williams, K. and Golding, L. (2017). Development and psychometric properties of the Psychological Therapies Outcome Scale - Intellectual Disabilities (PTOS-ID). *Journal of Intellectual Disabilities Research,* 61(6), 549-559.

15. Davis, C., Kellett, S. and Beail, N. (2009). Utility of the Rosenberg Self-Esteem Scale. *American Journal on Intellectual and Developmental Disabilities,* 114 (3), 172-178. *(Accessible widget version – in I CAN Evaluate resources from PELICAN: Promoting Emotional Literacy in Children with Additional Needs at PELICAN | Foundation for People with Learning Disabilities)*

16. Ishikawa, S., Takeno, Y., Sato, Y., Kishida, K., Yatagai, Y. and Spence, S. (2018). Psychometric Properties of the Spence Children's Anxiety Scale with Adolescents in Japanese High Schools. *School Mental Health,* 10 (3), 275-286. *(Accessible widget version – in I CAN Evaluate resources from PELICAN: Promoting Emotional Literacy in Children with Additional Needs at PELICAN | Foundation for People with Learning Disabilities)*

Appendices: 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)

Appendix 4 (cont.)

17. Wellbeing Award for Schools, Developed in partnership with the National Children's Bureau (NCB), pupil evaluation form.

18. Espie, C., Watkins, J., Duncan, R., Espie, A., Sterrick, M., Brodie, M., McGarvey, C. and Curtice, L. (2001). Development and validation of the Glasgow Epilepsy Outcome Scale (GEOS): a new instrument for measuring concerns about epilepsy in people with mental retardation. *Epilepsia,* 42(8), 1043-51.

19. Hastings, R. (2007). Measuring staff perceptions of challenging behaviour: the Challenging Behaviour Attributions Scale (CHABA). *Journal of Intellectual Disability Research,* 41(6), 495-501.

20. PBS Academy (2016). Providing Positive Behaviour Support. A Checklist for Service Providers. Available at: http://pbsacademy.org.uk/wp-content/uploads/2016/01/PBS-Academy-Service-Provder-checklist.pdf

21. Moore, J. (2019). An Evaluation of the Individualized Behavior Rating Scale Tool (IBRST) in Inclusive Classroom Settings. *Graduate Theses and Dissertations*, *University of South Florida*. Available at: https://scholarcommons.usf.edu/etd/7860

22. Sparrow, S., Cicchetti, D., and Balla, D. (2005). *Vineland-II Adaptive Behavior Scales: Survey Forms Manual.* Circle Pines, MN: AGS Publishing.

23. Richards, S. (2018). Exploring sexual knowledge and risk in the assessment and treatment of adolescent males with intellectual developmental disorders who display harmful sexual behaviour. *DForenPsy thesis, University of Nottingham.* Available at:

    http://eprints.nottingham.ac.uk/51891/1/Final%20Submission%20S%20Richards%20DForenPsy%20Thesis%20ID%20Number%204209884%20.pdf

24. BILD Capacity Assessment Tool. Available at:
    https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwjsw82F4aHwAhUIa8AKHb2tCcAQFjAAegQIAxAD&url=https%3A%2F%2Fwww.bild.org.uk%2Fwp-content%2Fuploads%2F2020%2F01%2FCAPACITY_ASSESSMENT_FOR_SEX_BILD-updated-16th-November-2020_.pdf&usg=AOvVaw2gs68peaPqeZvqVkTk4rRE

25. Rojahn, J., Rowe, E., Sharber, A., Hastings, R., Matson, J., Didden, R., Kroes, D. and Dumont, E. (2012). The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: part I: development and provisional clinical reference data. *Journal of Intellectual Disability Research,* 56(5), 527-45.

26. Raczka, R., Theodore, K. and Williams, J. (2020). An initial validation of a new quality of life measure for adults with intellectual disability: The Mini-MANS-LD. *Journal of Intellectual Disabilities*, 24(2), 177-193.

Appendices: 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)

Appendix 4 (cont.)

27. Eton, D., Ramalho de Oliveira, D., Egginton, J., Ridgeway, J., Odell, L., May, C., and Montori, V. (2012). Building a measurement framework of burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient related outcome measures,* 3, 39–49.

28. Dunsmuir, S., Brown, E., Iyadurai, S. and Monsen, J. (2009). Evidence-based practice and evaluation: from insight to impact. *Educational Psychology in Practice*, 25(1), 53-70.

29. Ruble, L., McGrew, J. H., & Toland, M. D. (2012). Goal attainment scaling as an outcome measure in randomized controlled trials of psychosocial interventions in autism. *Journal of autism and developmental disorders*, *42*(9), 1974-1983

30. Canadian Occupational Performance Measure. COPM COPM | Canadian Occupational Performance Measure (thecopm.ca)

31. Psychoeducational Diagnostic and Intervention Clinic (PEDIC). PEDIC | School of Education (uwi.edu)

APPENDIX 5

The number of respondents using each 'core' outcome measure with specific sub-groups of CYP; level of learning disability and age (Total N=95)

Measure	Level of learning disability (number of respondents)				Age group (years) (number of respondents)			
	Mild	Moderate	Severe	Profound	0-4	5-11	12-17	18-25
GBO	28	38	34	23	18	38	42	7
SDQ Parent	24	29	19	8	3	29	31	7
SLDOM	18	31	30	19	17	31	30	4
SDQ YP	23	15	8	6	3	16	28	3
CHI-ESQ	14	24	21	14	7	24	24	4
DBC	8	16	14	9	6	16	17	3
RCADS-P	16	9	1	0	12	13	16	2
SDQ Impact	11	16	13	6	1	16	16	1
BPI-01	5	10	14	6	4	11	12	4
CGAS	7	7	6	3	2	8	9	0
Nisonger	7	8	6	4	3	8	8	1

Appendices: 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)

APPENDIX 6

Qualitative analysis of themes from the 'Pros' and 'Cons' listed by respondents (with examples of specific comments) for each 'core' measure in the 2019 survey and comparison with 2015 survey (where available)

Measure	2019		2015	
	Pros	Cons	Advantages	Disadvantages
GBO	(N=38) Practicality/accessible (person-centred, easy to complete, relevant) Drives clinical processes (helps focus clinical work, helps parents notice and track change) Change is not expert led (empowering, person-centred, collaborative)	(N=6) Track/compare changes (can be difficult to track small changes) Skill in working with this measure (can be difficult to set clear and appropriate goals)	Practicality (quick and easy) Clinical validity (measures change, helps keep focus for work) Change is not expert led (reflective, person-centred/family specific) Appropriate to service user group (relevant and specific)	Clinical validity (goals may change over time) Skill in working with this measure (takes skill to collaboratively set goals)
CHI-ESQ	(N=17) Practicality (quick and easy) Differentiation between service/individual feedback (feedback about service and therapy) Accessibility (space for narrative comments)	(N= 15) Utility/accessibility (too simple, not completed confidentially) Overall purpose (do services act on feedback?)	Practicality (Quick and easy) Accessible (good way to get feedback) Clinically valid (qualitative meaningful data, captures change) Utility (collects important data for commissioners)	Appropriateness for service user group (difficult to complete for CYP with learning disabilities)

Appendices: 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)

Appendix 6 (cont.)

Measure	2019		2015	
	Pros	Cons	Advantages	Disadvantages
Nisonger	(N=7) Psychometric properties (detects change) Practicality (short, easy to complete For learning disability client group (validated for CYP with learning disabilities)	(N=5) Complexity for parents (confusing language, too long) Psychometric properties (may be less useful for CYP with severe/profound learning disabilities?)	Psychometric properties (gives indication of change for each subscale)	Complexity (too long and difficult to complete for clinician and parents)
SLDOM	(N=26) Appropriateness for service user group (learning disability specific, taps into pertinent factors) Practicality (Quick and easy) Facilitates engagement (generates conversation, facilitates engagement, gathers parent perspective) Psychometric properties (standardised measure)	(N=21) Accessibility (some questions wordy or emotionally challenging, sensitive, double negatives confusing, difficult to translate) Psychometric properties (subjective measure, not sure it is sensitive to change)	Practicality (easy and quick) Clinical validity (captures parents' feelings, can measure change)	Accessibility (positive and negative questions can be confusing, emotive wording) Clinical validity (not specific enough, not a measure of symptoms)
SDQ Impact	(N=8) Practicality (quick and easy) Clinical validity (detects change, captures impact not just behaviour)	(N=7) Clinical validity (not sensitive to the small changes typical in CYP with learning disabilities, too broad to show complexity)	N/A	

Appendices: 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)

Appendix 6 (cont.)

Measure	2019		2015	
	Pros	Cons	Advantages	Disadvantages
SDQ Parent	(N=20) Practicality (easy to complete, free) Psychometric properties (nationally recognised, normed)	(N=19) Appropriateness for service user group (unsuitable for moderate/severe learning disabilities) Clinical validity (not helpful information for clinicians) Psychometric properties (does not detect change in CYP with learning disabilities)	Practicality (ease of use) Clinical validity (covers range of CAMH concerns, useful to look at impact of service, impact score helpful) Psychometric properties (measures change)	Appropriateness for service user group (not appropriate for CYP with learning disabilities, parents feel clinician doesn't understand their child, questions worded ambiguously) Practicality (difficult for parents to complete) Psychometric properties (does not monitor change)
CGAS	(N=5) Practicality (quick, simple) Reliable source (rated by practitioners) Utility of clinical information (supports MDT discussion)	(N=6) Not approved measure (not appropriate for CYP with learning disabilities, subjective) Poor psychometric properties (not standardised, does not measure change)	N/A	

Division of Clinical Psychology · the british psychological society · CORC Child Outcomes Research Consortium

Appendices: 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)

Appendix 6 (cont.)

Measure	2019		2015	
	Pros	Cons	Advantages	Disadvantages
DBC	(N=15) Appropriate to service user group (best measure we have, tailored to learning disability group, relevant for LD CAMHS) Accessibility (speaks in language parents can associate with) Psychometric properties (standardised for CYP with learning disabilities, more useful than other measures for CYP with severe learning disabilities) Practicality (easy to score, quick if brief version) Engagement/aids clinical process (helpful for assessment not just outcomes)	(N=12) Practicality (long, cost) Accessibility (difficult if parents do not speak English) Psychometric properties	Appropriate to service user group (appropriate and relevant for CYP with learning disabilities) Clinical validity (measures change comprehensive and thorough) Practicality (easy and clear to complete) Aids clinical process (can look at exact behaviour trying to change, good as an assessment screening tool)	Practicality (lengthy, difficult to complete, cost) Accessibility (if English is not first language/literacy skills)
BPI-01	(N=7) Practicality (quick, easy to complete) Clinical validity/robust (sensitive, captures change)	(N=5) Accessibility (wording outdated and can be confusing) Selective or narrow in capturing presentations (not all items relevant, problem-focused)	Clinical validity/robust (looks in-depth at behaviours)	N/A

Appendix 6 (cont.)

Measure	2019		2015	
	Pros	Cons	Advantages	Disadvantages
RCADS-P	(N=10) Clinical validity (useful to monitor specific mental health issues)	(N=10) Psychometric properties (does not capture change in CYP with moderate to severe learning disabilities) Appropriateness for service user group (not learning disability specific, complex language)	N/A	
SDQ YP	(N=19) Meets data submission requirements (CYP-IAPT, nationally recognised) Practicality (quick and easy) Psychometric properties (can track changes, normed)	(N=20) Appropriateness for service user group (questions not appropriate, too complex, abstract, not cover behaviours seen in CYP with learning disabilities) Clinical utility (does not give a lot of useful information for this group)	N/A	

APPENDIX 7

Evaluation of the effectiveness of the Worcestershire Learning Disability CAMHS Team; analysis of 5.5 years' worth of outcome data

NB: All of the outcome measures used by the service are listed amongst the 'core' measures identified in this project

NHS
Herefordshire and Worcestershire Health and Care
NHS Trust

Learning Disability (LD) CAMHS Service Evaluation (July 2018) – a brief summary

How effective has the LD CAMHS Team been over the last 5 ½ years and how satisfied have parents/carers been with it?

Beth Smith and Kiran Badesha (Assistant Psychologists) recently conducted a comprehensive analysis of all outcome data collected routinely by the LD CAMH Service between September 2012 and April 2018. They subjected the data to rigorous statistical analysis and so were able not only to look at trends and changes as a result of LD CAMHS intervention, but also how confident we could be that these were significant and reliable.

Beth and Kiran were able to assess how effective the LD CAMHS team had been in terms of changes to:

- Young people's mental health/behaviour

- Parents'/carers' feelings of competence/confidence and understanding of their children's needs

- The impact of the difficulties on young people and their home/school life

- How close families felt they were to achieving the goals they agreed with the team

They were also able to report on the complexity of referrals, as well as how satisfied parents/carers were with the service received.

The main findings are summarised below.

Appendices: 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)

Appendix 7 (cont.)

MAIN FINDINGS

A.   COMPLEXITY OF REFERRALS

(Paddington Complexity Scale; not an outcome measure)

The mean score for referrals accepted for Partnership work was 19.0 which indicates that referrals are at least as complex as those found in other LD CAMHS services in the UK (where the mean has been found to be between 15.4 and 17.0). The team therefore is working with young people with needs of sufficient complexity to warrant input from a specialist learning disability service.
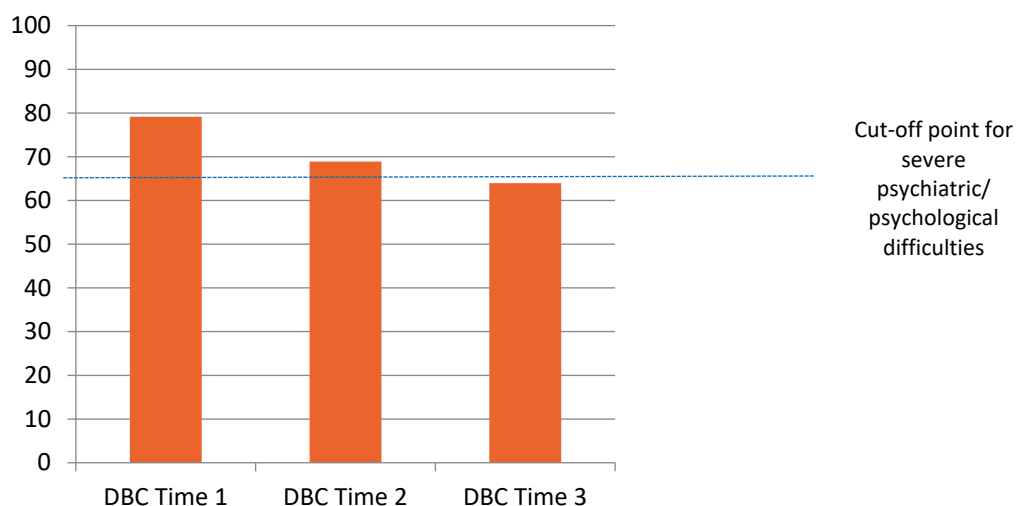
B.   OUTCOME MEASURES

Questionnaires were completed at the start of LD CAMHS involvement (time 1) then after 6 months (time 2) and 12 months (time 3) if the case was still open (if not then these were completed at closure).

Values for statistical significance (p) are quoted where applicable – p needs to be less than 0.05 for us to be confident that any changes are significant and reliable; the lower the value for p the more confident we can be in the findings (for example p=0.001 means that there is less a one in a thousand chance that it is wrong).

1.   Children and young people's mental health/behavioural difficulties

(Developmental Behaviour Checklist; DBC)

FINDING: Young people's symptoms of mental health/behavioural difficulties decrease significantly as the result of LD CAMHS interventions (and fall below the cut-off point for severe psychological/psychiatric difficulties; p=0.001 between time 1 and 2, p=0.005 between time 2 and 3)
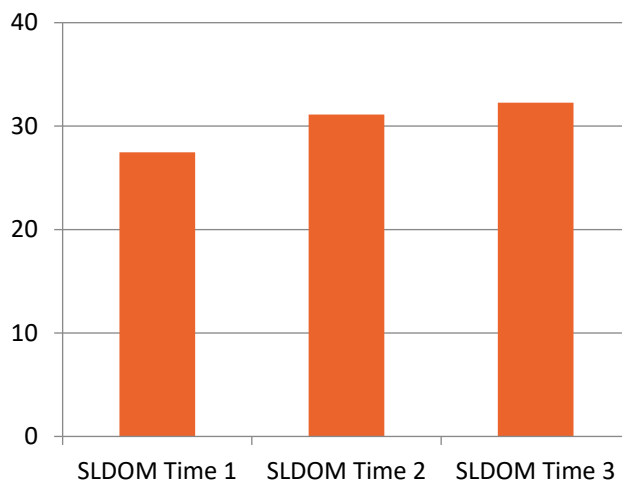
Appendix 7 (cont.)

1. Parent/carer competence, confidence and understanding

(Sheffield Learning Disability Outcome Measure; SLDOM)

FINDING: Parents/carers feel significantly more confident and competent and understand their child's needs more following LD CAMHS intervention and this continues to improve throughout involvement (p=0.001 and 0.001 respectively)

2. The impact of difficulties on children and young people and their home/school life

(Strength and Difficulties Questionnaire – impact assessment; SDQ Impact)

FINDING: The negative impact that a child/young person's difficulties have on their home life, learning at school, friendships and leisure time and the burden these difficulties place on their parents/carers all decrease significantly as a result of LD CAMHS involvement (p=0.001 and 0.048 respectively)
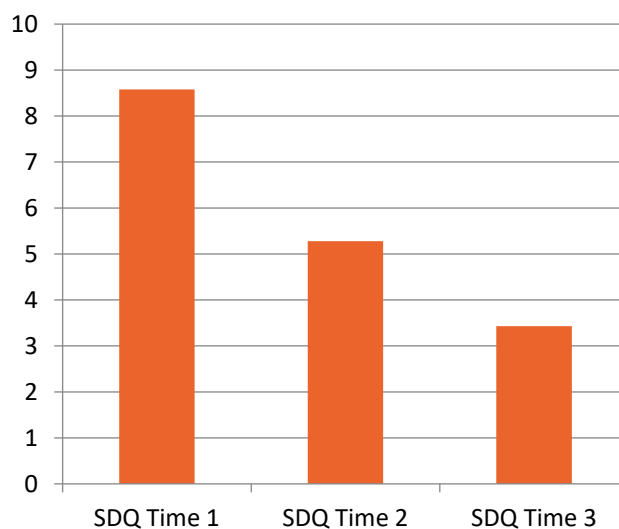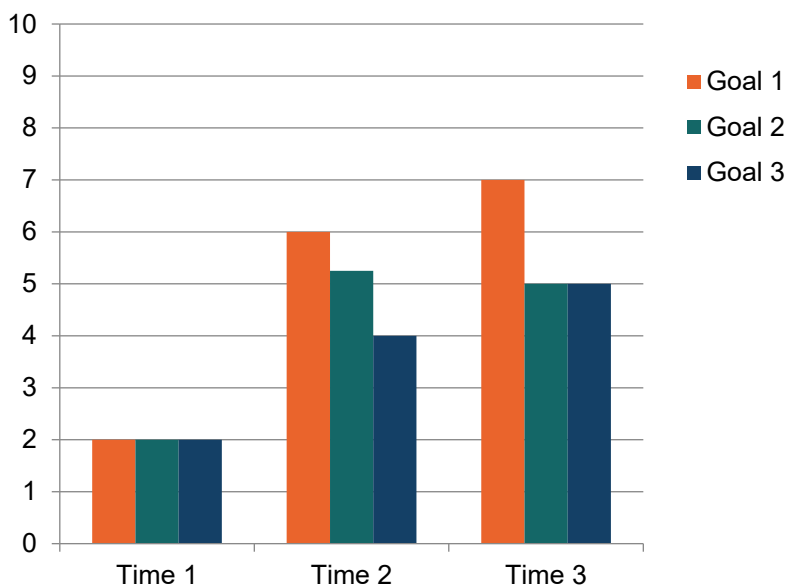
Appendix 7 (cont.)

2.   **Achieving goals**
(Goal Based Outcome; GBO)

FINDING: Families feel much closer to achieving the goals that they agree for LD CAMHS intervention by the end of the team's involvement (no statistical analysis conducted)

C.   **PARENT/CARER SATISFACTION**
(Experience of Service Questionnaire; ESQ/CHI-ESQ)

Parents/carers felt very satisfied with the service that they had received from LD CAMHS over the 5.5 year period and in particular:

*   93% said it was certainly true that they had received good help overall;
*   93% said they would certainly recommend the service to a friend (only 1% said they would not);
*   95-97% said it was certainly true that they felt listened to and that their views were taken seriously, that it was easy to talk to the LD CAMHS clinicians and that they were treated well by the service; and
*   93% said it was certainly true that appointments were arranged at times that were convenient for them so as not to interfere with work or school.

"What was really good about your care?" - themes from 88 comments:
*   Specialist knowledge/skills of the clinicians
*   Felt listened to and respected
*   Good communication
*   Flexible service
*   Person-centred
*   Multiagency working
*   Empowering, and
*   Supportive.
"Was there anything you didn't like or anything that needs improving?" – themes from 22 comments:

*   Wait between choice and partnership (staff vacancies since filled)

Appendices: 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)

31

- Quality of some rooms (building has since had a major renovation)