

the british
psychological society
promoting excellence in psychology



Division of
Clinical Psychology



Promoting equality and diversity in feedback and outcome measures for children and young people with learning disabilities

12th May 2021

Our agenda



-
- Introductions and overview of the project
 - Outcome Measures for Children and Young People with Learning Disabilities – findings and practice implications
 - Hearing the Voice of Children and Young People with Learning Disabilities – findings and practice examples
 - Discussion groups
 - Questions and Answers

Ro Rossiter

Ro is a clinical psychologist who's developed, delivered and evaluated innovative interventions and services for children, young people and adults with learning disabilities across multiagency settings for 40 years+!



Nick Tait

As Programme Manager at CORC, Nick works directly with members as well as on a range of projects in collaboration with CORC partner organisations.





Introducing the project



Why does this matter for me/us all?

- Broad range of children and young people across all settings – specialist and non-specialist: ‘neuro-typical’, SEND, ALN, LD, neurodevelopmental conditions, communication impairments, sensory and/or physical conditions
- Increase in numbers of children and young people with Complex Learning Difficulties and Disabilities (Carpenter et al., 2011; Blackburn et al., 2010), with increased survival of low-birth-weight babies and rise in Foetal Alcohol Spectrum Disorder etc (SSAT, 2017)
- Under-recognition of SEND etc, Simonoff et al. (2006) found, in a community sample, that only 15% of children with IQ < 70 had a statement of special educational needs in Years 8/9
- Equality Act requires ‘reasonable adjustments’ – if not identifying SEND, ALN, LD, neurodevelopmental conditions, communication impairments, sensory and/or physical conditions, can’t make appropriate ‘reasonable adjustments’

CYP-IAPT principles for Whole Service Transformation



Better evidence-based practice



Better collaborative practice and shared decision making



Authentic participation of families and Young People who have used or may use services



Rigorous outcomes monitoring

Leading to appropriate, accessible, effective and efficient services

Project Team

Ro Rossiter

Nick Tait

Neil Phillips

Stream lead for the measures and methods, survey update and analysis, Hereford & Worcestershire Care Trust.

Eric Emerson

Stream lead for interrogation of MCCS data on SDQ, Lancaster and Sydney Universities.

Jeni McElwee

Stream lead for Profound and Multiple LD participation & service users, Anuerin Bevan UHB, Wales.

Duncan Law

Director of MindMonkey Associates, Programme Director at the Anna Freud Centre & Honorary Associate Professor at UCL Faculty of Brain Science.



Project Team



Commissioning expertise:

Angela Kirton Commissioning Manager, Children's Community Health Commissioning Team, Worcestershire County Council (2019)

Harry Harrison Commissioning Manager, Children's & Families; NHS North Cumbria Clinical Commissioning Group (2020/2021)

Aims

Summarise context and findings from the project including:

- sharing results from our survey of current practice regarding use of outcome measures with children and young people with Learning Disabilities, their families, carers and networks

- share a framework to support people to hear the 'voice' of children and young people especially those with severe or multiple and profound learning disabilities and some good practice initiatives and resources

Provide opportunities for you to share and reflect upon examples from your own practice regarding what works well



Using outcome measures with Children and Young People with Learning Disabilities

-
- Project findings
 - Implications for practice

How do we do it?

Step 1

Gathering quantitative data:

- Analysis of CORC dataset
- Practitioner Survey

Step 2

Gathering qualitative data:

- Qualitative survey responses
- Workshops

Step 3

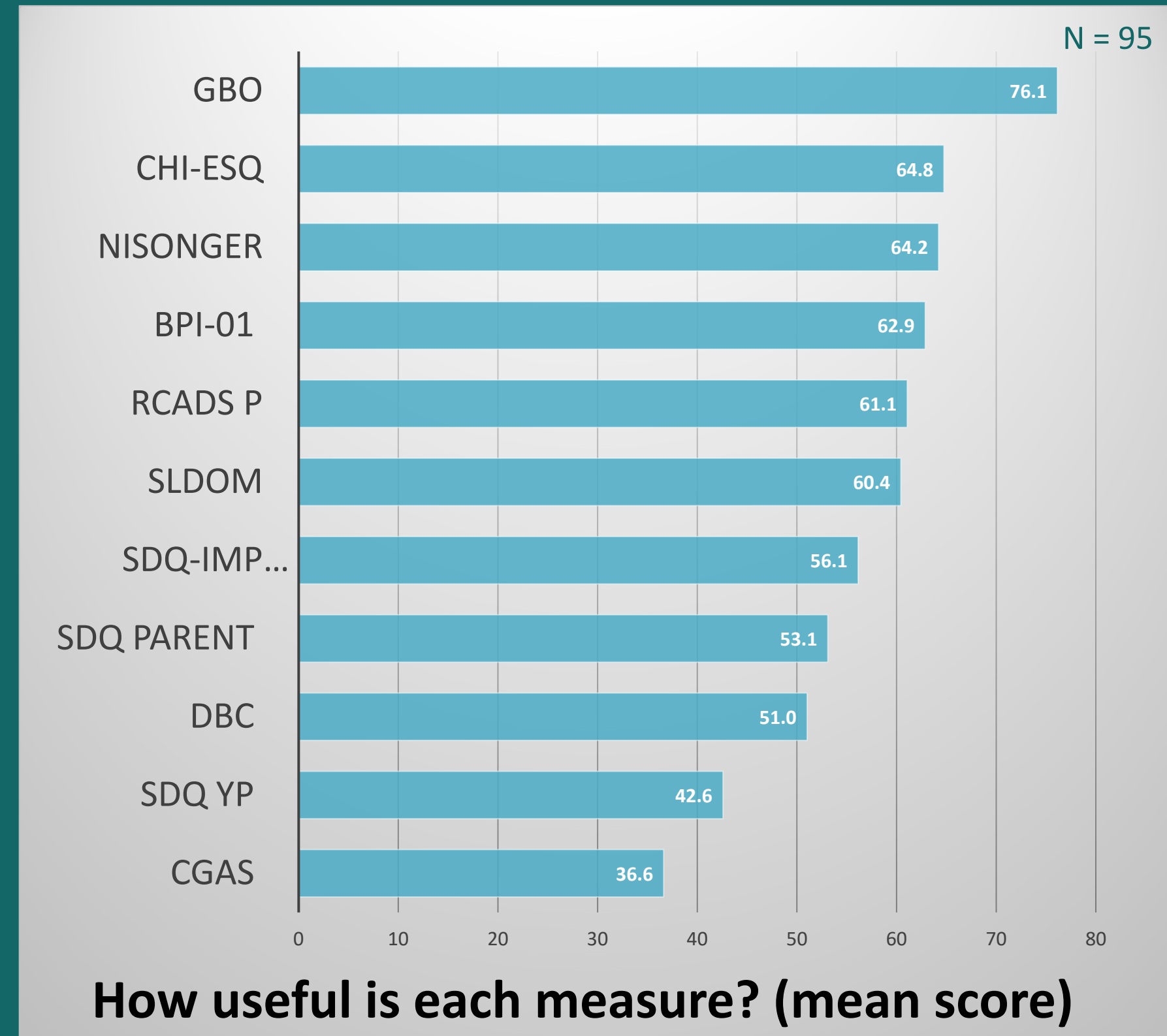
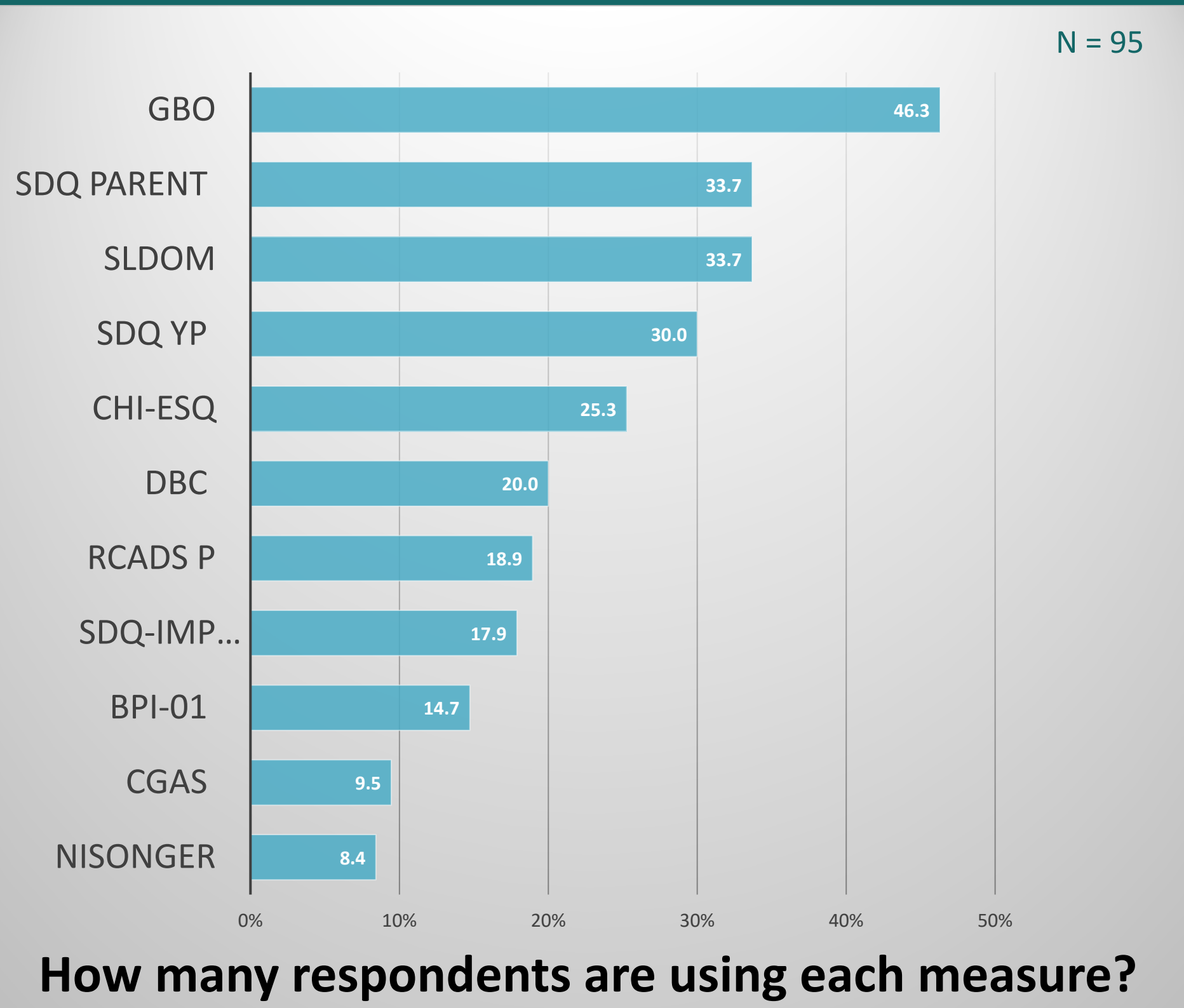
- Analysis of quantitative findings
- Implications for practice

The Survey

The key elements were:

- Demographic information about the practitioner and their service
- The outcomes used routinely
- For each outcome measure follow-up questions about
- Which CYP the practitioner typically uses the measure with:
 - Level of learning disability of the CYP
 - Age group
- Practitioner ratings of clinical utility on a scale from 0-100;
 - How useful the practitioner finds it and how well it detects change
 - How useful and easy to complete parents/carers/young people find it (or practitioners for practitioner-rated measures)
 - Pros and cons of each measure
- Further questions about data collected/submitted and any direct feedback from parents/carers/CYP and whether the practitioner would be willing to share this

Results - survey



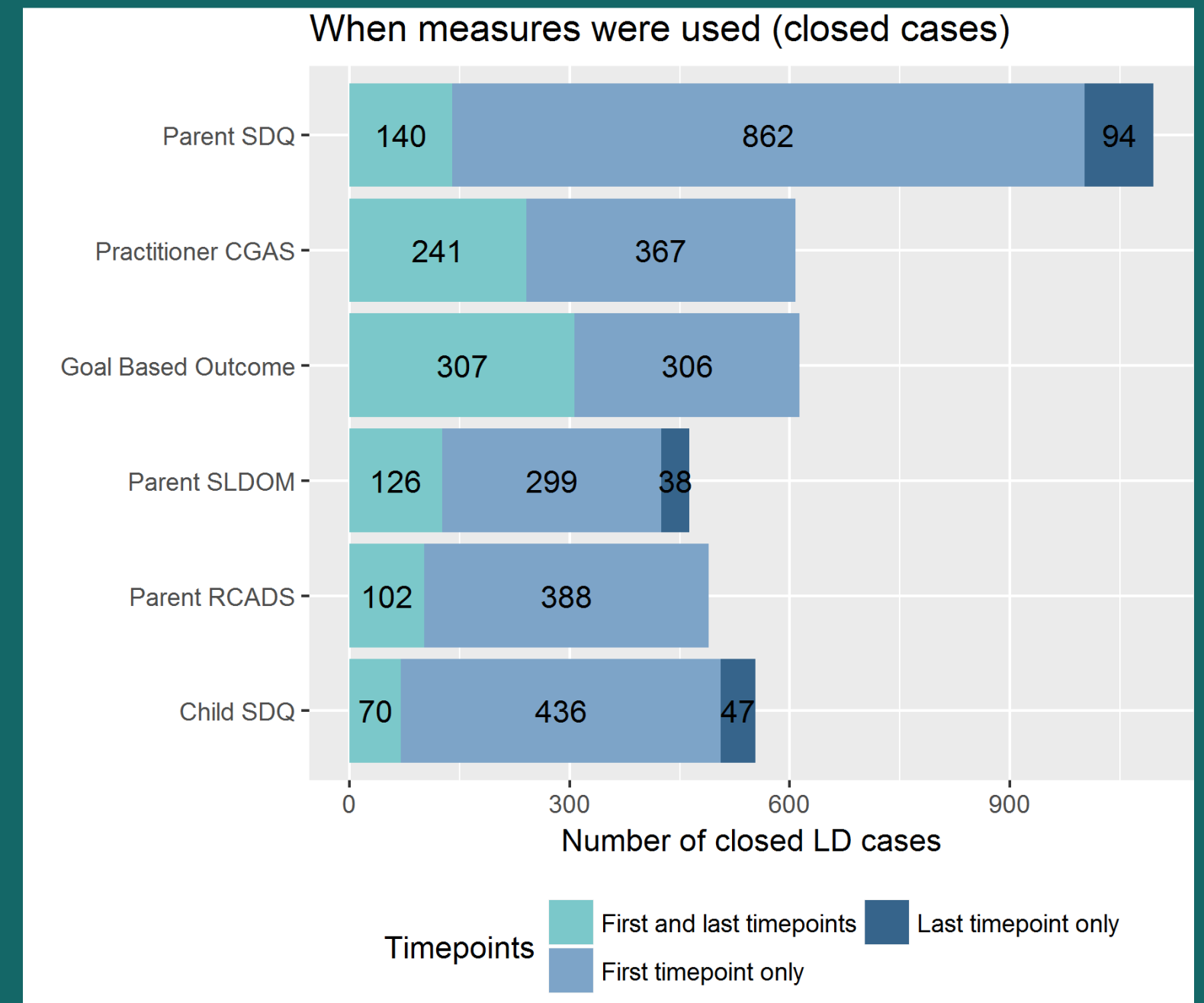
GBO = Goal Based Outcomes; SDQ Parent/YP/Imp Supplement= Strengths and Difficulties Questionnaire Parent/Young Person version/Impact Assessment part only; SLDOM = Sheffield Learning Disabilities Outcome Measure; CHI-ESQ = Experience of Service Questionnaire; DBC = Developmental Behaviour Checklist; RCADS P = Revised Children's Anxiety and Depression Scale Parent Version; BPI-01 = Behavior Problem Inventory; CGAS = Children's Global Assessment Scale; Nisonger = Nisonger Child Behavior Rating Form

Results - survey

Outcome measure use by group (nb red = <50% green = >50%)	Level of learning disability				Age group (years)			
	Mild	Moderate	Severe	Profound	0-4	5-11	12-17	18-25
GBO	Green	Green	Green	Green	Red	Green	Green	Red
CHI-ESQ	Green	Green	Green	Green	Red	Green	Green	Red
Nisonger	Green	Green	Green	Green	Red	Green	Green	Red
SLDOM	Green	Green	Green	Green	Green	Green	Green	Red
SDQ – Imp Supplement	Green	Green	Green	Red	Red	Green	Green	Red
SDQ Parent	Green	Green	Green	Red	Red	Green	Green	Red
CGAS	Green	Green	Green	Red	Red	Green	Green	Red
DBC	Red	Green	Green	Red	Red	Green	Green	Red
BPI-01	Red	Green	Green	Red	Red	Green	Green	Green
RCADS-P	Green	Red	Red	Red	Red	Green	Green	Red
SDQ YP	Green	Red	Red	Red	Red	Green	Green	Red

Results – CORC dataset

- The measure used most at two timepoints in closed learning disability cases is the **Goal Based Outcome** tool
- The Goal Based Outcome tool was used as often at two timepoints as at a first timepoint only
- Other measures were used more often at a first timepoint only than at two timepoints



Results - Qualitative Analysis

Those that are felt to be appropriate for use with CYP with learning disabilities

- o GBO
- o CHI-ESQ
- o SLDOM
- o DBC
- o BPI-01
- o Nisonger

Those that may be appropriate but perhaps with some reservations

- o SDQ Impact

Those that may be appropriate for the most able CYP with learning disabilities

- o SDQ Parent
- o RCADS P

Those that are not appropriate

- o CGAS
- o SDQ YP

SUMMARY OF FINDINGS

MEASURE	LEVEL OF LD (tick indicates routinely used with this group)				CLINICAL UTILITY Tick indicates 'good' cross indicates 'poor'					QUALITATIVE ANALYSIS Appropriate for use with CYP with learning disabilities?
	Mild	Moderate	Severe	Profound	Practitioner		Parent/carer		Overall clinical utility	
					Useful?	Detects change?	Useful?	Easy?		
GBO	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
CHI-ESQ	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
SLDOM	✓	✓	✓	✓	✓	✗	✗	✓	✓	✓
Nisonger	✓	✓	✓	✓	✓	✓	✗	✗	✓	✓
BPI-01	✗	✓	✓	✗	✓	✓	✓	✓	✓	✓
DBC	✗	✓	✓	✗	✓	✗	✗	✗	✗	✓
RCADS P	✓	✗	✗	✗	✓	✗	✓	✗	✓	Mild LD only
SDQ Parent	✓	✓	✓	✗	✗	✗	✗	✓	✗	Mild LD only
SDQ Impact	✓	✓	✓	✗	✗	✗	✗	✓	✗	?
SDQ YP	✓	✗	✗	✗	✗	✗	✗	✗	✗	✗
CGAS	✓	✓	✓	✗	✗	✗	✗	✗	✗	✗

Recommendations:

Recommended measures for use with all CYP with learning disabilities (i.e. across all ability levels).

- GBO
- CHI-ESQ
- SLDOM
- Nisonger

This represents a balanced mix of measures across all three areas of measurement

Additional measures for use with CYP with moderate to profound learning disabilities

- BPI-01
- DBC

Additional measures for use with CYP with mild learning disabilities

- RCADS P

Pause for thought

How have issues around equality and diversity impacted on your approach to measuring outcomes and change?

How has the COVID 19 pandemic impacted on your approach to measuring outcomes and change?

Think about what are you doing to measure outcomes and change for CYP you work with, including any 'reasonable adjustments for those with LD, SEND, ALN and/or neurodevelopmental conditions, and?'

Write your thoughts in the 'chat' line

Hearing the 'voice': why is this important?

- **Enshrined in Rights** – including rights to be given the opportunity to influence their goals and own care, eg express what they like and don't like; learn that they have the right to, and can make, choices
- **Enshrined in law** (e.g. Children and Families Act, 2014; Social Services and Wellbeing (Wales) Act 2014)
- **Increase participation and empower:** children, young people and families may know themselves the best; have some clear ideas about what is helpful and not helpful
- **Co-production:** services more responsive, safe, personalised and efficient

Hearing the voice: how do we do it?

Step 1

- Network – existing practice, resources, organisations
- Literature review
- Synthesise to 'interim web grid' to share and gather more

Step 2

- Generate framework for conceptualizing impact of hearing the 'voice'
- Gather 'good practice initiative' examples using Framework; what helps; barriers
- Workshops

Step 3

- Curating 'good practice initiative' examples to share
- Thematic analysis of 'good practice initiative' examples Consultations with cyp Integrate learning and identify implications for practice

Hearing the 'voice' for what? ... where and how children and young people can make an impact



Hearing the 'voice' – how including all abilities & 'voices'?

Valuing the views of children with a learning disability
Engaging with children and young people with severe or profound and multiple learning disabilities

Options

Top Scale

My wider world

www.talkingmats.com

me ncap

Truth & Lies
Helping children explain the difference

how it is
An image vocabulary for children about feelings, rights and safety, personal care and sexuality

'Opening Doors': best practice when a young child might be showing or telling you that they are at risk

Examples of good practice from “Interim summary grid” for Hearing the Voice * in References, resources, links list

- Valuing the views of children with a learning disability (Challenging Behaviour Foundation & Mencap)
- Talking Mats www.talkingmats.com
- Nick Gore - Goals and Outcomes For Intervention “GO-For-It”: Child and Family Views Project –child and parent interviews – use of Talking Mats, activities, observations (Gore & McGill, 2019)
- “If you listen, you will hear us ” Leicester Partnership NHS Trust; video: https://youtu.be/Hp4PW17U_h8 shows how personalised ways of communicating- nonverbal gestures, day-to-day behaviours, e.g. eye-blink, change of colour in face can ensure all are included in decisions which impact on their lives & help evaluate and plan services
- www.triangle.org.uk – communication, safeguarding, social/legal justice - resources, training, investigative interviewing, intermediaries

Hearing the voice and measuring change : symbols and pictures

e.g. Widget/Communicate in Print <https://www.widgit.com/index.htm>

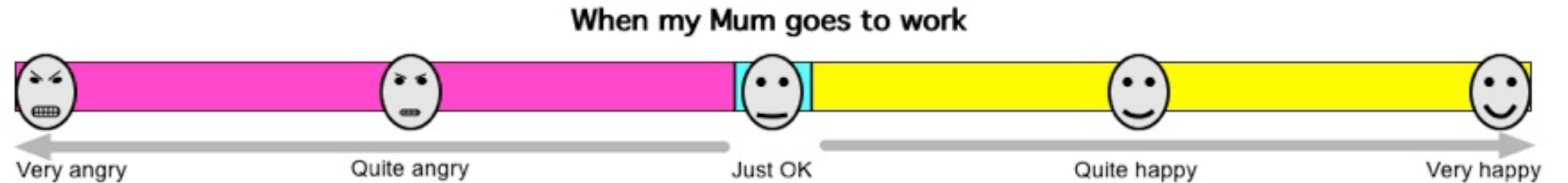


Photosymbols <http://www.photosymbols.com/>

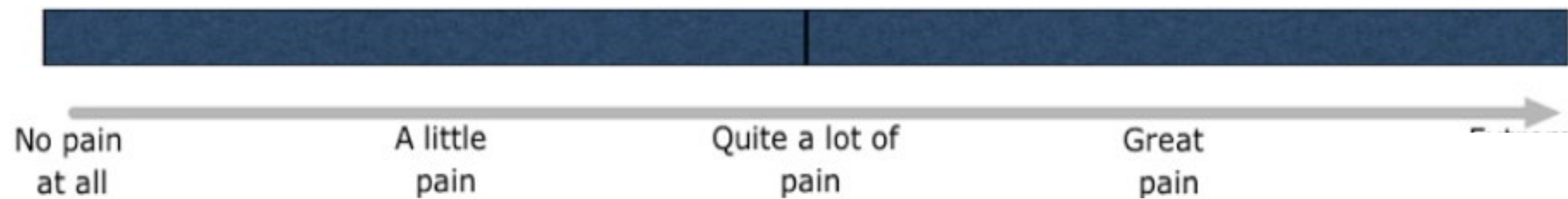


Hearing the voice and measuring change:

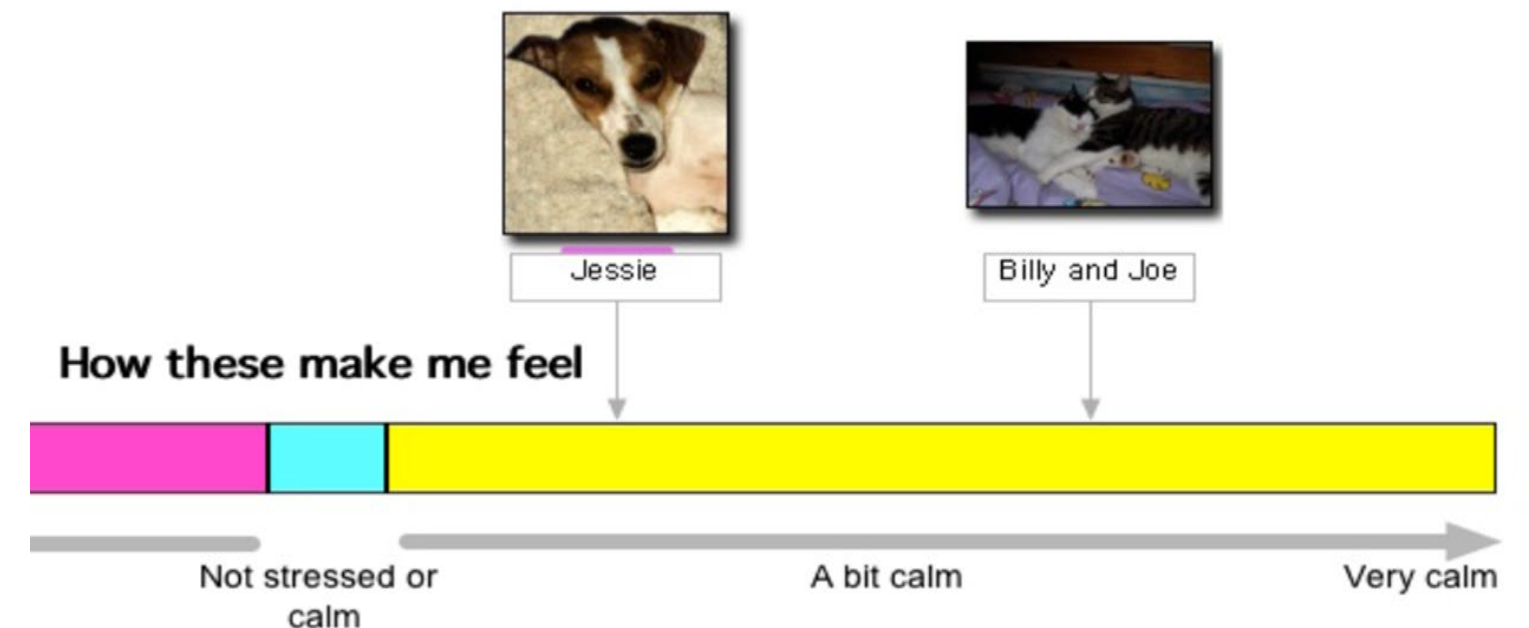
- **Visual Analog Scales (VAS) & This Much!** Helping professionals to help children (2012) David V Glasgow <https://itunes.apple.com/gb/app/this-much!/id571631245?mt=8> (also This Much! for iPad) E.g. Bipolar scale with icons and context. The colours were selected to be relatively easily discriminated by individuals with red-green colour blindness.



Unipolar scale



- **Customise with pictures, words e.g. squirmy, anxious & situations**



Hearing the voice and measuring change – ‘Good Practice initiatives’ (egs from Project 1)

- Adapted self-report measure/screen of mental health and behaviour, Me & My Feelings (Me & My School), Deighton et al. (e.g. of adapted response scale)
- Visual aids- integral.
- Each item printed individually, presented to the child in turn and read aloud to them with presenting the visual aids for yes/no



- Sometimes or always visuals used if the child responded ‘yes’, e.g. with the follow-up question of ‘do you have problems with your sleep sometimes or always?’

Sometimes



Always



Emma Jackson & Biza Stenfert Kroese

Original Me & My Feelings in Wellbeing Measurement Framework for Primary Schools.

https://www.corc.uk.net/media/1506/primary-school-measures_310317_forweb.pdf

Hearing the voice and measuring change – ‘Good Practice initiatives’ (egs from Project 2)

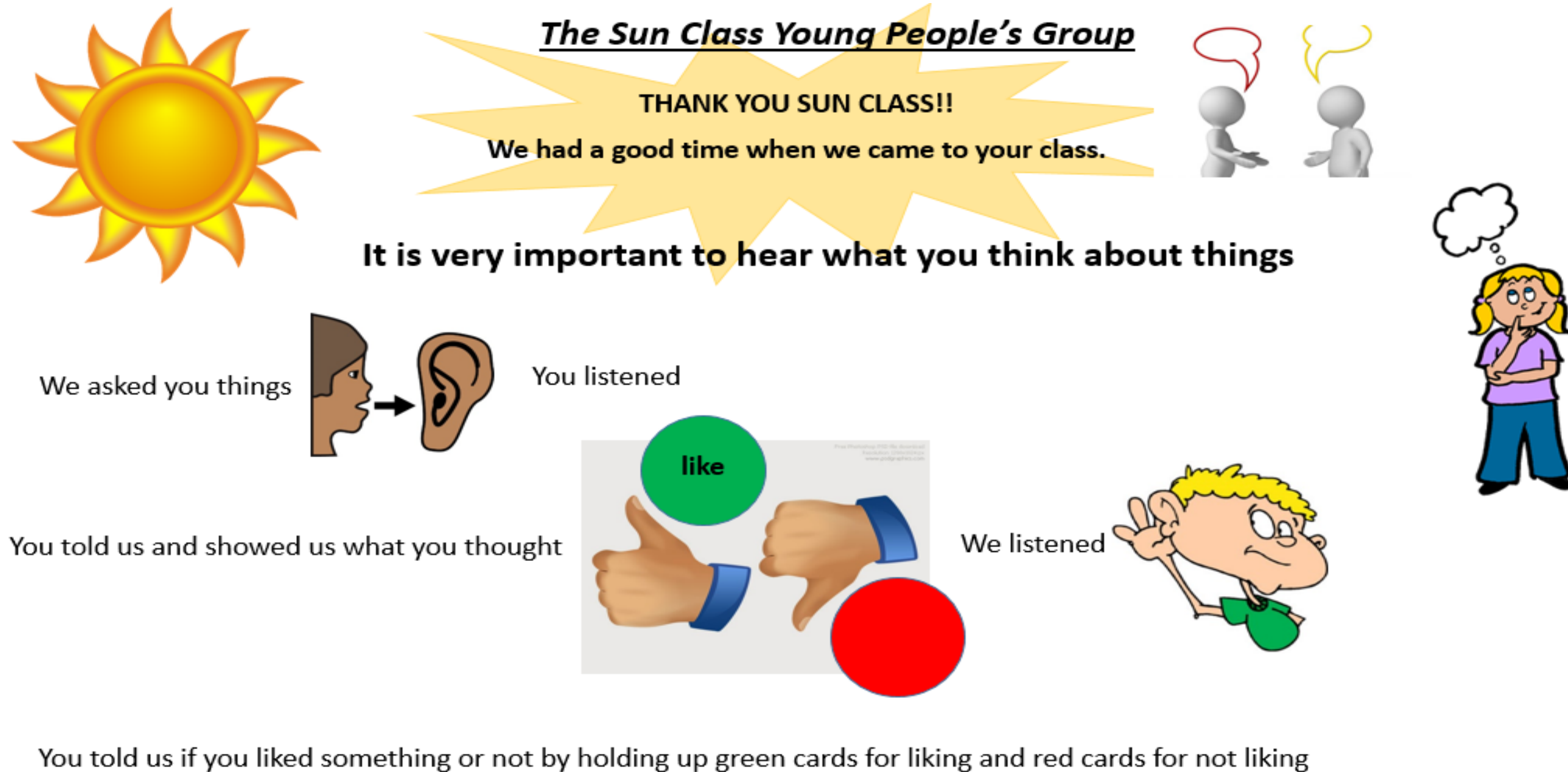
- **Participation in action:** Sharing Suns Gemma Watts, Andrew James, Sam Greedy*
- **Sharing Suns:** engaging in an activity where the class were asked to go in groups round the school and take pictures of things they like and things they don't like about their school.



Hearing the voice and measuring change – ‘Good Practice initiatives’ (egs from Project 2)

- **Participation in action: Sharing Suns Feedback loop**

*Andy James, Gemma Watts, Sam Greedy**










Hearing the voice and measuring change – ‘Good Practice initiatives’ (egs from Project 2)

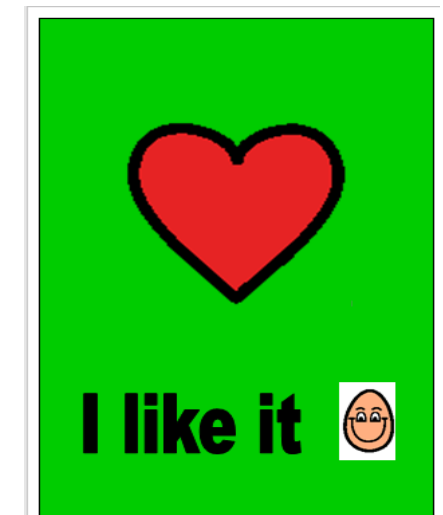
- **Participation in action:** Sharing Suns - consistency, predictability, routine

*Andy James, Gemma Watts, Sam Greedy**



Name:

					
 I like it					
 I don't like it					



Hearing the voice and measuring change – ‘Good Practice initiatives’ (egs from Project 3)

Observational frameworks *Jennifer McElwee, Emma Alm, Lucy Bennett Downes*

- A. Parent/carer interview (assessing what candidate says)

What would you like to know about (child/young person’s name)?

- B. Time spent with (child/young person’s name) (assessing what candidate does)

Use observational frameworks

- C. Feedback

Overall parent/carer impression

Would you want to work with (candidate name)?

Would (child/young person’s name) want to work with this candidate?

What is your overall impression? Is this candidate appointable?

Feedback from candidate about interview process



Hearing the voice and measuring change – ‘Good Practice initiatives’ (egs from Project 3)

Observational frameworks – staff interviews

Jennifer McElwee, Emma Alm, Lucy Bennett Downes

(i) Is (child) engaged?

Indicators of (child)’s engagement:

Indicator	Not present (0)	Partially present (1)	Fully present (2)
Smiling			
Eye contact			
Initiating interaction			
Following/copying the candidate’s lead			
Engaged body language e.g. animated body movements			
Specific signs of (child)’s engagement: Add signs			

Additional comments

Hearing the voice and measuring change – ‘Good Practice initiatives’ (egs from Project 3)

Observational frameworks – staff interviews

Jennifer McElwee, Emma Alm, Lucy Bennett Downes

(ii) What does the candidate do to try to engage (child)?

Indicator	Not present (0)	Partially present (1)	Fully present (2)
Smiling			
Eye contact			
Initiating interaction e.g., using visuals/objects of reference, signing			
Following/copying the child/young person’s lead e.g. alter tone/speed of voice according to context			
Engaged body language e.g. getting on the same level as the child			

Does this vary according to need?



Discussion groups

In your groups...

- What's going well?
- What are the barriers?

Feedback – choose a spokesperson to feed back THREE examples of what's going well and THREE barriers or challenges

Next steps

Final report

Currently being drafted

Review and publication

Lead by British Psychological Society

Dissemination

Through CORC newsletters and social media

Follow up events

Opportunities for sharing more widely





Contact us

r.rossiter@kent.ac.uk

nick.tait@annafreud.org

The link to the interim grid of useful resources for Hearing the 'voice' of children and young people with moderate, severe or multiple and profound learning disabilities is at:

<https://www.bps.org.uk/member-microsites/division-clinical-psychology/projects>



References & resources

- BPS/DCP Racial and social inequalities: Taking the conversations forward: Racial and Social Inequalities in the Times of Covid-19 Working Group <https://www.bps.org.uk/member-microsites/division-clinical-psychology/equality>
- Challenging Behaviour Foundation/Mencap Valuing the views of children with a learning disability <https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/Valuing-the-views-of-children-with-a-learning-disability.pdf>
- CORC info Project video and link to some resources: <https://www.corc.uk.net/news-blogs/corc-collaborates-in-project-to-grow-best-practice-in-using-outcome-measures-in-cyp-with-learning-difficulties/>
- Using outcome measures with young people from different ethnicities and in different countries <https://www.corc.uk.net/news-blogs/using-outcome-measures-with-people-from-different-ethnicities-and-in-different-countries/>



References & resources

- CORC Forum 2020 breakout sessions info
<https://sway.office.com/AwQiOSPOEwITRZOb?ref=Link>
- Slides for Session 1 Getting future -ready: what are we learning about working with outcome and feedback measures remotely? <https://www.corc.uk.net/media/2698/corc-forum-presentations-bo-session-1.pdf> and Session 6 Diversity in measurement – what are some current challenges, opportunities and best practices?
<https://www.corc.uk.net/media/2703/diversity-in-measurement-corc-forum-2020.pdf>
- <https://www.corc.uk.net/resource-hub/corc-forum-november-2020/>
- Consensus guidance (2015) see <https://www.corc.uk.net/media/2692/cyp-ldfeedback-roms-final-logos.pdf>
- Emerson, E. 2020 Use of the Strengths and Difficulties Questionnaire for Monitoring the Wellbeing of Children and Young People With Learning Disabilities
<https://www.bps.org.uk/member-microsites/division-clinical-psychology/projects>



References & resources

- Gore, N. J. & 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 <https://link.springer.com/article/10.1007/s10826-019-01398-5>
- 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://link.springer.com/article/10.1007/s10826-020-01867-2>
- [James, A. & families Day 1 What participation means to us Andy James and families](#)
- [Watts, G. & Fry, C. Day 1 Participation in Action Gemma Watts and Charlotte Fry](#)
- James, A.& Creedy, S. Day 1 *We talk, you listen Team Epic Andy James and Sam Creedy*
- All 3 above presentations at <https://www.bps.org.uk/member-microsites/dcp-faculty-people-intellectual-disabilities/events> from “Our Journey Together: People with Learning Disabilities and Clinical Psychologists in Partnership” conference



References & resources

- Hickey, S. & Taylor-Whiteway, S. nd. Listening to unheard voices:an experiential introduction to thinking about how to hear and capture the voices of children who cannot communicate to us verbally. [SENCoForumPupilVoicePowerpoint\(1\).pdf](#)
- Law, D. & Jacob, J. Goals and Goal Based Outcomes (GBOs) some useful information. See <https://www.corc.uk.net/media/1219/goalsandgbos-thirdedition.pdf>
- Law, D. 2019 *The goal-based outcome (GBO) tool: guidance notes*. MindMonkey Associates: London. <https://goalsintherapycom.files.wordpress.com/2019/02/gbo-version-2.0-guide-final-1st-feb-2019.pdf>
- Midgen, T., Theodoratou, T., Newbury, K. & Leonard, M. (2019). ‘School for everyone’: An exploration of children and young people’s perceptions of belonging. *Educational and Child Psychology*, 36(2), 9–22. ‘School for Everyone’: An exploration of children and young people’s perceptions of belonging | [Request PDF \(researchgate.net\)](#)



References & resources

- Midden, T., Theodoratou, T., Newbury, K. & Leonard, M. (2019). 'School for everyone': Our Top Ten Tips to Help us Feel we Belong. DECP Conference. (PDF) School for Everyone: Our Top Ten Tips to Help us Feel we Belong ([researchgate.net](https://www.researchgate.net))
- Mulligan, B., John, M., Coombes, R. & Singh, R. (2014) Developing Outcome Measure for a Family Intensive Support Service for Children presenting with Challenging Behaviour. [British Journal of Learning Disabilities](#).
- Phillips, et al. (2013) Are we making a difference? Measuring the value of our work with children and young people with a learning disability and behaviour that challenges their families. In Intellectual Disabilities and Challenging Behaviour, ACAMH Occasional Paper No 32, eds Lovell, M. & Udwin, O.
- Pill J., with Shrubsole, S. & Draper, E. (2013) Can CYP IAPT Routine Outcome Measures be used in a meaningful way with CYP-LD & their Families? CYP-IAPT Leadership Project 2012-2013



References & resources

- Rossiter, R., Armstrong, A., Morgan, S. & Phillips, N. (2013) Same or different? Measuring outcomes in children and young people with learning disabilities, their families and networks. *Child and Family Psychology Review*, 1, 84-92.
- Rossiter, R. & Armstrong, A. (2015) Using goals in clinical practice : Children and young people with learning disabilities, their parents/carers and networks Children and young people with learning disabilities. Chapter in Law, D. & Jacob, J. *Goals and Goal Based Outcomes (GBOs) some useful information*. See <https://goals-in-therapy.com/using-goals-with-children-young-people-with-learning-disabilities/>
- Rossiter, R. et al. (2014) *Learning Disabilities: collecting and use of feedback with children and young people with learning disabilities*. Chapter in *Guide to using outcomes and feedback tools with children and young people*. Eds Law, D. & Wolpert, M. CORC, IAPT, Evidence Based Practice Unit, Anna Freud Centre, UCL. Available at: [https://www.corc.uk.net/media/2112/201404guide to using outcomes measures and feedback tools-updated.pdf](https://www.corc.uk.net/media/2112/201404guide_to_using_outcomes_measures_and_feedback_tools-updated.pdf)



References & resources

- Simonoff E, Pickles A, Chadwick O, Wood N, Maney JA, Karia N, Iqbal H, Moore A (2006). The Croydon Assessment of Learning Study: prevalence and educational identification of mild mental retardation. *Journal of Child Psychology and Psychiatry* 47, 828–839.
- “Special Measures?” Project info/links: News on BPS web
<https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Divisions/D/CP/Special%20Measures%20Project%20-%20July%202020%20Update.pdf>
- “Interim summary grid” for Hearing the Voice - <https://www.bps.org.uk/member-microsites/division-clinical-psychology/projects>
- <https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Divisions/D/CP/Special%20Measures%20Project%20-%20Stream%203%20-%20Hearing%20the%20Voice.pdf>

CORC ADDRESS

4-8 Rodney Street,
London N1 9JH

PHONE NUMBER

+44 (0)20 7443 2225

EMAIL ADDRESS

corc@annafreud.org

TWITTER

[@CORCcentral](https://twitter.com/CORCcentral)

CONTACT INFORMATION

