



the british  
psychological society  
promoting excellence in psychology



Division of  
Clinical Psychology



**The table below signpost links for useful organisations, people, practice developments and resources to support ‘Hearing the Voice’ / gathering feedback – especially voices often not heard e.g. Profound and Multiple Learning Disabilities (PMLD).**

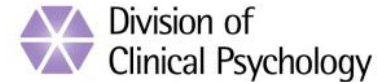
---

The table was generated from project consultations, literature reviews, networking and workshops. Others are found in [Good Practice examples](#).

---

**Find more information here:**

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

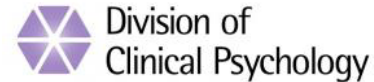



Some coronavirus resources based on Hearing the Voice and/or supporting Hearing the Voice of CYP-LD and their families are in red.

Name of organisation, people, practice developments, resources	What is the focus or nature of the organisation/resource/practice?	Web-links
Aneurin Bevan University Health Board, Jeni McElwee	Co-produced initiative to involve CYP-LD of all ages/abilities and families in staff selection through active participation. Observation framework and guidance.	<a href="https://www.corc.uk.net/media/2872/creation-of-an-observational-framework-to-support-young-people-who-communicate-in-ways-other-than-language-to-contribute-meaningfully-to-staff-recruitment.pdf">https://www.corc.uk.net/media/2872/creation-of-an-observational-framework-to-support-young-people-who-communicate-in-ways-other-than-language-to-contribute-meaningfully-to-staff-recruitment.pdf</a>
Ask, listen, do (NHSE)	NHSE project about making conversations count across health, education and social care for people with LD of all ages. Examples, video's on web. Initially rather adult-focused – our project linked with Mary Busk, Family Carer Adviser NHSE and co-founder of the National Network of Parent Carer Forums to encourage more CYP involvement and focus.	<a href="http://www.england.nhs.uk/asklistendo">www.england.nhs.uk/asklistendo</a>
Avon and Wilts Partnership NHS Trust and Bristol Special Schools	Team Epic, participation group at Claremont School – see presentations from “ <i>Our Journey Together: People with Learning Disabilities and Clinical Psychologists in Partnership</i> ” conference and ‘Hearing the voice’ good practice example summary 3 ‘ <b>Team Epic Participation Group</b> ’	<a href="https://www.bps.org.uk/member-microsites/dcp-faculty-people-intellectual-disabilities/events">https://www.bps.org.uk/member-microsites/dcp-faculty-people-intellectual-disabilities/events</a> - presentations: <ul style="list-style-type: none"> <li>• Day 1 Participation in Action Gemma Watts and Charlotte Fry</li> <li>• We talk, you listen Team Epic Andy James &amp; Sam CreedyDay 1 What participation means to us Andy James and families</li> </ul> <a href="https://www.corc.uk.net/media/2861/team-epic-participation-group.pdf">https://www.corc.uk.net/media/2861/team-epic-participation-group.pdf</a>

Find more information here:


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



British Association of Social Work (BASW)	<i>Homes not Hospitals</i> , 2021. Co-produced campaign & resources- key element is listening to people (plus families) to get services right in community and prevent admissions.	<a href="http://www.basw.co.uk">BASW England launches Homes not Hospitals campaign   www.basw.co.uk</a>
Challenging Behaviour Foundation (CBF)	<p>Co-authors with Mencap of ‘<i>Valuing the views of children with a learning disability; engaging with children and young people with severe or profound and multiple learning disabilities</i>’</p> <p>CB-NSG March 2020 focused on Outcomes – see summary and actions, including:          -workshop on “Hearing the Voice of children, young people and families in order to achieve good outcomes”          -poster on Special Measures Project</p> <p>“<i>Stop, Look and Listen to Me</i>” (2021) based on methods developed by CBF &amp; Nick Gore (Tizard Centre) gathering views from children and young people with severe learning disabilities and behaviours described as challenging.</p> <p>The <i>Seldom Heard</i> 2021 project (NHSE funded) builds on and extends existing good practice around listening to and involving people with severe and profound learning disabilities</p> <p>coronavirus resources includes info, FAQ re law, templates, returning to school</p>	<p><a href="https://pavingtheway.works/whats-new/valuingtheviewsblog/">https://pavingtheway.works/whats-new/valuingtheviewsblog/</a></p>  <p><a href="https://www.challengingbehaviour.org.uk/driving-change/information-from-meetings/cb-nsg-6thmarch-2020.html">https://www.challengingbehaviour.org.uk/driving-change/information-from-meetings/cb-nsg-6thmarch-2020.html</a></p> <p><a href="https://www.challengingbehaviour.org.uk/learning-disability-assets/specialmeasuresro.pdf">https://www.challengingbehaviour.org.uk/learning-disability-assets/specialmeasuresro.pdf</a></p> <p><a href="http://www.challengingbehaviour.org.uk">Stop, Look and Listen to me (challengingbehaviour.org.uk)</a></p> <p><a href="http://www.challengingbehaviour.org.uk">Seldom Heard - Challenging Behaviour Foundation</a></p> <p><a href="https://www.challengingbehaviour.org.uk/information/all-our-resources.html">https://www.challengingbehaviour.org.uk/information/all-our-resources.html</a></p>

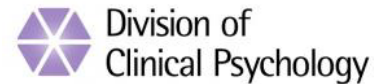
Find more information here:

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

<p>Council for Disabled Children (CDC)</p>	<p>Participation projects and guidance eg <i>Listening to Young Disabled Children</i></p> <p>Participation- summaries of policy, useful resources including: Participation and Engagement Audit Tool Monitoring and Evaluation Factsheet Literature review on the participation of disabled children and young people in decision making Amanda Allard qualitative research with CYP with neurodisability and parents re outcomes; CHUMS- collaboration of NIHR, University of Exeter, Cerebra; use of Talking Mats – see below</p> <p><b>Links to resources for families and also professionals in health, education and social care</b></p>	<p><a href="https://www.ncb.org.uk/sites/default/files/field/attachment/Listening%20to%20Young%20Disabled%20Children.pdf">https://www.ncb.org.uk/sites/default/files/field/attachment/Listening%20to%20Young%20Disabled%20Children.pdf</a></p>  <p><a href="https://councilfordisabledchildren.org.uk/our-work/participation/Participation%20Audit%20Tool%20-%20Council%20For%20Disabled%20Children">https://councilfordisabledchildren.org.uk/our-work/participation/Participation Audit Tool   Council For Disabled Children</a></p> <p><a href="https://councilfordisabledchildren.org.uk">Introduction (councilfordisabledchildren.org.uk)</a></p> <p><a href="https://councilfordisabledchildren.org.uk/sites/default/files/field/attachment/CHUMS%20Report%20Allard.pdf">https://councilfordisabledchildren.org.uk/sites/default/files/field/attachment/CHUMS%20Report Allard.pdf</a></p> <p><a href="https://councilfordisabledchildren.org.uk/help-resources/resources/covid-19-support-and-guidance#parent%20carers">https://councilfordisabledchildren.org.uk/help-resources/resources/covid-19-support-and-guidance#parent%20carers</a></p>
<p>Foundation for People with Learning Disabilities</p>	<p>Long history of hearing the voice eg on mental health and cyp-ld, early reports:</p> <ul style="list-style-type: none"> <li>• Count us in</li> <li>• Making Us Count</li> </ul>	<p><a href="https://www.mentalhealth.org.uk/learning-disabilities/our-work/health-well-being/count-on-us">https://www.mentalhealth.org.uk/learning-disabilities/our-work/health-well-being/count-on-us</a></p> <p><a href="https://www.mentalhealth.org.uk/learning-disabilities/our-work/health-well-being/making-us-count">https://www.mentalhealth.org.uk/learning-disabilities/our-work/health-well-being/making-us-count</a></p>
<p>Juliet Goldbart, Manchester</p>	<p>Co-author “<i>Communication and people with the most complex needs: What works and why this is essential</i>”</p>	<p><a href="https://www.mencap.org.uk/sites/default/files/2017-05/Mencap%20Comms%20guide%20dec%2010.pdf">https://www.mencap.org.uk/sites/default/files/2017-05/Mencap%20Comms guide dec 10.pdf</a></p>

**Find more information here:**

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



<p>Metropolitan University</p>	<p>Expertise in “Pre-intentional and early intentional communication intervention strategies” - see conference presentation &amp; “<i>Affective Communication Assessment (ACA)</i>” Coupe-O’Kane &amp; Goldbart. Available from Melland High School, 50 Wembley Road Gorton Manchester M18 7DT, UK</p> <p>Co-Investigator on IASC - Identifying Appropriate Symbol Communication Aids for Children who are non-speaking: clinical decision making project. NIHR grant</p>	<p><a href="#">Prof. Juliet Goldbart - Communication Strategies for People with Profound Intellectual Disability - YouTube</a></p> <p>IASC study findings and resources on their web <a href="https://iasc.mmu.ac.uk/research-findings/">https://iasc.mmu.ac.uk/research-findings/</a></p>
<p>Intensive Interaction</p>	<p>Intensive Interaction helps people at early levels of development, with severe, profound or complex learning difficulties and/or autism, develop/enjoy fundamentals of communication. Information, training, videos on web. Improves engagement, can alter staff/carers/peers perceptions of, and interactions with, people and have beneficial effects with challenging behaviour and trauma</p>	<p><a href="https://www.intensiveinteraction.org/">https://www.intensiveinteraction.org/</a></p> <p><a href="#">McKim, J, Samuel, J. The use of Intensive Interaction within a Positive Behavioural Support framework. <i>Br J Learn Disabil.</i> 2021; 00: 1–9</a> <a href="#">Samuel, J. &amp; Doswell, S. (2021) “The use of Intensive Interaction in trauma-informed care for people with severe and profound intellectual disabilities” in <i>Trauma and Intellectual Disabilities: Acknowledgement, Identification and Intervention.</i> Eds Beail, N., Frankish, P. &amp; Skelly, A. Pavilion.</a></p>
<p>Leicester NHS <i>If you listen you will hear us</i></p>	<p>SALT led Project to increase communication with, &amp; inclusion of people with more severe impairments. Although more adult-focused, some are young adults and the processes and principles apply across ages</p>	<p>See video: <a href="https://www.youtube.com/watch?v=Hp4PW17U_h8">https://www.youtube.com/watch?v=Hp4PW17U_h8</a></p>
<p>Me first</p>	<p>Co- developed Me First CYP communication model (Great Ormond Street Hospital and Common Room); extension project for/with CYP-LD &amp; 5 pilot training days (HEE funding) with Triangle (see below*) &amp; Ro Rossiter (May 2019)</p>	<p><a href="https://www.mefirst.org.uk/">https://www.mefirst.org.uk/</a></p>
<p>Nick Gore, clinical psychologist &amp; Jill</p>		<p>Gore, Nick J. and McGill, Peter (2019) Making it Meaningful: Caregiver Goal Selection in Positive Behavioral Support. <i>Journal of Child and Family Studies</i>, online (online). pp. 1-10. ISSN 1062-1024.</p>

**Find more information here:**

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



Bradshaw, SALT/Talking Mats trainer see below**) & researchers / lecturers, Tizard, University of Kent	"Go for IT -Goals and Outcomes of Interventions" project interviewing people who know child/young person with severe LD & behaviour described as challenging well, then tailor making personalised approach to gathering views from CYP-LD, eg 'Talking Mats', photos, objects of reference; observation	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 <a href="https://doi.org/10.1007/s10826-020-01867-2">https://doi.org/10.1007/s10826-020-01867-2</a> Open access - <a href="https://rdcu.be/cc8ec">https://rdcu.be/cc8ec</a>
Office of the Children's Commissioner	'They still need to listen more!': A report about disabled children and young people's rights in England.	<a href="https://childrenscommissioner.gov.uk">'They still need to listen more'   Children's Commissioner for England (childrenscommissioner.gov.uk)</a>
Openstorytellers, Nicola Grove	Useful website- resources, info, guidance & and training on storytelling.	<a href="https://www.openstorytellers.org.uk/what-we-do/storysharing/">https://www.openstorytellers.org.uk/what-we-do/storysharing/</a>
PAMIS	Scotland based charity; PAMIS - Promoting a more Inclusive Society. Focus on PMLD  updated digital leaflet 2021  Virtual activity programme for COVID times  Digital passport template	<a href="http://pamis.org.uk/">http://pamis.org.uk/</a>  <a href="https://pamis.org.uk/site/uploads/pamis-generic-leaflet-2021-final-copy.pdf">https://pamis.org.uk/site/uploads/pamis-generic-leaflet-2021-final-copy.pdf</a>  <a href="http://pamis.org.uk/services/virtual-activity-programme/">http://pamis.org.uk/services/virtual-activity-programme/</a> <a href="http://pamis.org.uk/news/news/passports-for-all-pamis-digital-passports-covid-19-offer/">http://pamis.org.uk/news/news/passports-for-all-pamis-digital-passports-covid-19-offer/</a>
PMLD Link	<i>Raising Our Sights communication guide</i> - communicating with people with PMLD.	<a href="http://www.pmlmlink.org.uk/resources/#communication">http://www.pmlmlink.org.uk/resources/#communication</a> <a href="https://www.mencap.org.uk/advice-and-support/pmld/pmld-involve-me">https://www.mencap.org.uk/advice-and-support/pmld/pmld-involve-me</a>

**Find more information here:**

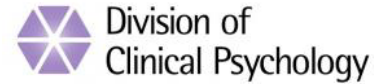
<https://www.corc.uk.net/outcome-experience-measures/feedback-and-outcome-measures-for-children-and-young-people-with-learning-disabilities/>



Speakup	Speakup & Sheffield Sparkle project ' <i>Listening to Seldom Heard Voices</i> ' (NHSE funded) to hear what they think about Health inequalities, Reducing inpatient numbers and Developing new service frameworks for CYP -key working & intensive community support	<a href="#">Home   Speakup Main Website</a>  <a href="#">Seldom heard voices   Speakup Main Website</a>
Talking Mats**	<p>Framework, process, resources, research, training, videos to support communication/hearing the voice</p> <p>Example of using Talking Mats for goal setting and decision making Poster of using Talking Mats in self advocacy- setting goals and leisure access Project on Inclusive Research 'Research Voices Evaluation Report: What we learned from this project'</p> <p><b>Easy read information on coronavirus with Talking Mat designed symbols</b></p> <p><b>Talking Mats Set to support Reflecting on Lockdown</b></p>	<p><a href="https://www.talkingmats.com/">https://www.talkingmats.com/</a></p> <p><a href="https://www.talkingmats.com/wp-content/uploads/2013/09/Goal-setting-TMOT-2.pdf">https://www.talkingmats.com/wp-content/uploads/2013/09/Goal-setting-TMOT-2.pdf</a></p> <p><a href="https://www.talkingmats.com/wp-content/uploads/2020/01/AAC-Poster-RCSLT-Conference-September-2019.pdf">https://www.talkingmats.com/wp-content/uploads/2020/01/AAC-Poster-RCSLT-Conference-September-2019.pdf</a></p> <p><a href="https://www.talkingmats.com/wp-content/uploads/2020/07/Lockdown-Set.pdf">research-voices-evaluation-easy-read-final.pdf (sldo.ac.uk)</a></p> <p><a href="https://www.talkingmats.com/wp-content/uploads/2013/09/20200319-coronavirus-easy-read-pdf.pdf">https://www.talkingmats.com/wp-content/uploads/2013/09/20200319-coronavirus-easy-read-pdf.pdf</a></p> <p><a href="https://www.talkingmats.com/wp-content/uploads/2020/07/Lockdown-Set.pdf">https://www.talkingmats.com/wp-content/uploads/2020/07/Lockdown-Set.pdf</a></p>
Tools for Talking	Tools co-developed with people with LD to support exploring and understanding issues around diversity, culture and beliefs and people (Rose et al., 2013). Can be used with people with learning disabilities, their families and networks. Though developed with adults, the framework and materials could be used with younger ages.	<p><a href="https://toolsfortalking.wordpress.com/">https://toolsfortalking.wordpress.com/</a></p> <p>Videos and resources to help discussions around 'My Culture and what it means to me'; 'Important People in my life and my relationships with them'; 'Things I do now and things I would like to do'.</p>
Triangle*	an independent organisation with over 20 years' experience, enabling children and young people, especially those with complex needs, from very young up to age 30, to communicate about important things, especially in legal proceedings. Their "vision is to reposition children	<p><a href="https://www.triangle.org.uk/">https://www.triangle.org.uk/</a></p> <p>There are videos, resources, papers eg How it is image vocabulary: <a href="https://www.triangle.org.uk/files/2017-05/how-it-is-2002-an-image-vocabulary-for-children.pdf">https://www.triangle.org.uk/files/2017-05/how-it-is-2002-an-image-vocabulary-for-children.pdf</a></p>

**Find more information here:**

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



	<p>and young people in society as competent communicators and active agents in their own lives". They provide advocacy, consultation, expert opinion, intermediary services, investigative interviewing, research, resources (some downloadable free from web), specialist support, therapy, training. Collaborators in Me first "extension" pilot for CYP-LD</p>	<p>How young is too young paper re evidence of under 5's in CJS: <a href="https://www.triangle.org.uk/files/2017-05/-how-young-is-too-young-ruth-marchant-2013.pdf">https://www.triangle.org.uk/files/2017-05/-how-young-is-too-young-ruth-marchant-2013.pdf</a> Opening doors framework- showing how a listening adult may need to play an active, enabling role, and respond to what a child 'does' as well as what they 'say': <a href="https://triangle.org.uk/files/Documents%20(various)/2017-marchant-turner-opening-doors-ilovepdf-compressed-1-.pdf">https://triangle.org.uk/files/Documents%20(various)/2017-marchant-turner-opening-doors-ilovepdf-compressed-1-.pdf</a></p>
--	---	---

---

**Find more information here:**

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