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Division of
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A NOTE ON THE LANGUAGE USED IN THE PROJECT MATERIALS

Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)

There are many views and issues underlying the use of language, labels, and terminology^{1, 2, 3}. Concerns can include de-personalisation, over-medicalisation, invalid and unhelpful categories and constructs, over-emphasis on individual 'pathology' whilst ignoring systemic factors and strengths, labelling and identity issues, stigma and discrimination, limiting responses and/or 'paternalistic' approaches and lack of involvement of experts by experience. Helpful aspects can include assisting understanding and explanation, feeling less 'alone', access to information, support, services and funding, efficient service design and research. Here, we explain some of the way that the project and materials use language, and why.

Find more information here:

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

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USE AND MEANING OF THE WORDS “SPECIAL MEASURES?”

The Project title we were granted funds for is:

“Special measures?” - equality and diversity in feedback and outcome measures: progressing practice and practice-guidance on measures and methods for children and young people with learning disabilities (LD), their families and networks.

Below are 4 things to note about the use and meaning of the words “Special measures?”:

1. “Special measures?” was put in italics and “quotation marks” with the question mark to signal some uncertainties about the concept and the wording.
2. Our idea of “Special measures?” linked to the range of measures that can be used to facilitate the gathering and giving of evidence by vulnerable and intimidated witnesses introduced by the Youth Justice and Criminal Act (YJCEA) known as “special measures”. Eligibility applies automatically to child witnesses under the age of 18 and some Disabled People.
3. In analysis, discussion and workshops based on previous surveys, “Special measures?” had been used as a shorthand for wondering if different measures and/or different ways of using existing measures were needed.
4. We did not have in mind the ‘Special measures’ status applied by OFSTED to services who fall short of acceptable standards.

The title for project learning reports and resources is now *‘Gathering feedback and measuring outcomes and change with Children and Young People with Learning Disabilities (LD)’*.

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USE OF THE WORDS ‘GATHERING FEEDBACK’ AND ‘MEASURING OUTCOMES AND CHANGE’

For **‘Gathering Feedback’** the project takes this as hearing, listening to and promoting the ‘voice’ of children and young people with moderate, severe or multiple and profound learning disabilities (where ‘voice’ should be interpreted as meaning communication, in whichever form works best for the child or young person). This is important at all stages of assessment, planning and review, in individual and service contexts and includes direct feedback from children and young people. The project’s [multi-level map of change, impact and feedback](#) shows how this is important across different levels, as health and wellbeing are affected by many broad, contextual factors.

For **‘Measuring outcomes and change’** the project takes this as including standardised, published and idiographic (personalised) measures for individuals, and also broader service data across different levels.

USE OF THE WORDS ‘CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES (LD)’

Below are some things to note about the use of the words ‘children and young people with learning disabilities (LD)’:

1. There continues to be debate, and some inconsistency, around terminology and ‘learning disabilities’. This project uses the term ‘learning disabilities’ as this reflects the most preferred, and the most consistently used, term amongst people with learning disabilities and practitioners in the UK.
2. ‘Learning disabilities’ is used in the plural form to denote a range of abilities/disabilities in a range of children and young people.
3. We look to the current Department of Health (DH) definition of Learning Disability in their policy and practice documents:
 - significantly reduced ability to understand new or complex information, to learn new skills
 - reduced ability to cope independently which starts before adulthood with lasting effects on development (Department of Health, Valuing People: A New Strategy for Learning Disability for the 21st Century, 2001).
 - ‘reduced ability to understand new or complex information, to learn new skills’ refers to impairment of intelligence (usually 2 or more standard deviations below the mean on a validated test of general cognitive functioning/equivalent to an IQ score of less than 70)
 - ‘reduced ability to cope independently’ refers to impairment of social functioning measured on social or adaptive functioning measures
4. The extent and nature of these impairments are found in 2.5% of children. This is a smaller group than the 20+% of children with ‘Specific Learning Difficulties’ (SpLD).
5. It is important to remember that children and young people with learning disabilities are very heterogeneous- with a very varied and wide range of cognitive abilities and impairments in learning and information processing abilities. Any IQ figure only gives very limited information about the nature of strengths and weaknesses in information processing and abilities.

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6. Strict 'cut-offs' or boundaries may not be helpful/appropriate. Access to assessment may be lacking- if additional needs are not recognised, adjustments can't/won't be made. Sometimes, assumptions are made about cognitive level and functioning on the basis of softer observations of language, which may not be accurate and are often too high. These issues were identified in the Barnardo's (2016) report of the parliamentary inquiry into support and sanctions for children who display harmful sexual behaviour 4 including:
 - additional needs of young people who had a diagnosed learning disability who had experienced, or been at risk of, child sexual exploitation (CSE)
 - those with a learning need, who had not been formally assessed or who may not have received any additional support to help them in their learning
 - unmet learning needs that played a part in placing them at risk of CSE or had led to them being sexually exploited
7. Other factors affect learning abilities/disabilities including neurodevelopmental conditions (e.g. autism, ADHD), developmental experiences (e.g. Adverse Childhood Experiences, abuse, trauma), neurological conditions (e.g. epilepsy, brain injury), sensory impairments, mental health conditions and the effects of medication, as well as the ability/disability of environments and services to meet individuals' needs.
8. Our project's aim was to focus on children and young people with learning disabilities, and to ensure that those with the most complex needs were included. As we considered the issues above, along with feedback from consultations and broader considerations of equalities, diversity and inclusion from our original project title and then amplified following the murder of George Floyd, we realised attention was needed to broader neurodiversity and the full range of protected characteristics, and their intersectionality, under the Equality Act.

CURRENT LEGISLATIVE DEFINITIONS

It is also worth reminding ourselves of some current legislative definitions:

A child or young person is considered to have special educational needs and disabilities (SEND) ...

“if they have a learning difficulty or disability which calls for special educational provision to be made for him or her” (Children and Families Act 2014: p.19).

In the Revised SEND Code of Practice, children’s SEND are included within four broad areas of need and support:

communication and interaction; cognition and learning; social, emotional and mental health; sensory and/or physical needs.

Many children and young people with SEND may also have a disability as defined under the Equality Act 2010 as...

“a physical or mental impairment which has a long-term and substantial adverse effect on their ability to carry out normal day-to-day activities.”

which calls for the provision of ‘reasonable adjustments’ as do all other ‘protected characteristics’ under the Act.

The words we use, hear and see influence our thinking, feelings and what we do. Our project learning has shown that oftentimes barriers faced by children and young people with learning disabilities, their families and networks are attitudinal and maybe influenced by unconscious biases and assumptions.

The Crown Prosecution Service (CPS) in their updated, April 2021, on Special Measures⁵ describes well how this can happen and what to do differently...

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The CPS understands the social model of disability to mean that the prejudice, discrimination and social exclusion experienced by many disabled people is not the inevitable result of their impairments or medical conditions, but rather stems from specific barriers they experience on a daily basis. These barriers can be environmental (inaccessible buildings and services), attitudinal (stereotyping, prejudice and discrimination), and organisational (inflexible policies, practices and procedures).

Using the social model helps us to dismantle or reduce the effects of those barriers that are within our power, and improve the safety and security of disabled people.

Reporting a crime, giving a statement and being called to give evidence in court can be very daunting experiences for anyone. Prosecutors should recognise that disabled people can experience specific barriers in this regard. These can include a failure by criminal justice agencies to identify an incident as a potential disability hate crime, inaccessible courtrooms, witness waiting areas or an absence of sign language interpreters.

Prosecutors must avoid incorrect judgments being made about disabled people's reliability or credibility as a witness giving evidence in court. Such judgments may lead to an incorrect charging decision or could undermine the potential success of a prosecution.

Prosecutors will therefore:

- Not make assumptions about a disabled victim's reliability or credibility, and challenge others who do so;
- Ensure that disabled people are aware of the support that is available to them to give their best evidence;
- Be more likely to prosecute cases where disability is a factor, including disability hate crimes where there is sufficient evidence to do so;
- Be mindful that language is important and only use the term 'vulnerable' in relation to disabled people when it is appropriate in the context of the law and facts of the case; and
- Recognise that the stereotype-based belief that a disabled person is 'vulnerable' forms the backdrop of disability hate crime and crimes against disabled people and can even be a motivating factor in crimes committed against them.

Many different words and labels are in use – learning disabilities, additional learning needs, developmental delays, developmental disorders, neurodevelopmental conditions, SEND. In the project materials, the language used reflects the source it came from.

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REFERENCES

1. Rossiter, R. & Arena, R. (2021). What's in a name? Findings, issues and reflections on diagnosis – an update from a Faculty Survey. *Clinical Psychology Forum*; 339; March; pp 56-66.
2. British Psychological Society (2018). *The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour as an alternative to functional psychiatric diagnosis*. Leicester: British Psychological Society.
3. British Psychological Society (2013). *Division of Clinical Psychology Position Statement on the Classification of Behaviour and Experience in Relation to Functional Psychiatric Diagnoses Time for a Paradigm Shift*. Leicester: British Psychological Society.
4. Barnardo's (2016) "Now I know it was wrong: Report of the parliamentary inquiry into support and sanctions for children who display harmful sexual behaviour". Barnardo's; Ilford.
5. [Special Measures | The Crown Prosecution Service \(cps.gov.uk\)](https://www.cps.gov.uk/special-measures)