





Protocol: Working with parents with a diagnosed learning disability and parents with a mild or borderline learning disability

Overview of key contextual issues to consider when developing local policies and protocols.

Local authorities are free to tailor this document to meet their own requirements, but are asked to credit the use of this document as follows: Tarleton, MacIntyre and Tilbury (2024) Template: Joint working protocol regarding parents with learning disabilities, University of Bristol.

Section 1: Key guidance documents

'Good Practice Guidance on working with parents with a learning disability' (GPG) <u>FINAL</u> 2021 WTPN UPDATE OF THE GPG.pdf (bristol.ac.uk)

This is not statutory guidance but has been endorsed by both the previous and current President of the Family Division:

'My primary purpose in issuing this [President's] Guidance is to bring to the attention of practitioners and judges, and to commend for careful consideration and application by everyone, the very important "Good practice guidance on working with parents with a learning disability" issued by the Working Together with Parents Network and the Norah Fry Centre in September 2016.'

Sir James Munby Family Proceedings: Parents with a Learning Disability - Courts and Tribunals Judiciary

That guidance [GPG 2021] should also be at the forefront of local authority planning. That would give intellectual focus and rigour to the evaluation of parental strengths and weaknesses in cases, whether before the courts or not. Cases which come before the courts involving a parent with learning disabilities should, as a matter of good practice, be capable of demonstrating that the guidance has been taken into account in any care planning or proposals put forward by a local authority.'

Sir Andrew McFarlane endorsing the above words of High Court Judge Mrs Justice Knowles Speech by the President of the Family Division: Parents with intellectual impairment in public law proceedings - the need to be alert - Courts and Tribunals Judiciary

The GPG (originally issued by the Department of Health and the Department for Education and Skills in 2007 and updated by the Working Together with Parents Network (WTPN) in 2016 and 2021) identifies five

key features of good practice in working with parents with learning disabilities, which to varying degrees are common to all parents with disabilities:

- 1. Accessible information and communication.
- 2. Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways.
- 3. Support designed to meet the needs of parents and children based on assessments of their needs and strengths.
- 4. Long-term support where necessary.
- 5. Access to independent advocacy.

Other guidance and good practice documents

'Supporting parents who have learning disabilities: Strategic Briefing' (2018) Working with parents who have a learning disability | Research in Practice

'What Works for Parents with Learning Disabilities? – Summary' Author: Susan McGaw Report Published: 2000 WWPARWLD.DOC (choiceforum.org)

'Successful professional practice when working with parents with learning difficulties': GTC SUMMARY REPORT 16.5.2018 designed.pdf (bristol.ac.uk)

'Supporting parents with learning disabilities and difficulties Stories of positive practice': positivepractice.pdf (bristol.ac.uk)

'Substituted parenting: What does this mean for parents with learning disabilities in the family court context?' Nadine Tilbury and Beth Tarleton (2023). Includes an example 'Template for analysis of Risk and options to address risk' bristol.ac.uk/media-library/sites/sps/documents/wtpn/SP Report.pdf

Section 2 – About parents with learning disabilities and best practice when working with parents with learning disabilities

This section is presented in the following parts:

- Parents with learning disabilities their lives and contexts
- Recognition and screening of parental learning disability
- Key principles when working with parents with a diagnosed learning disability or a milder/borderline learning disability
- Assessing parents' capacity to parent and their support needs
- Positive practice

Parents with learning disabilities – their lives and contexts

People with learning disability are amongst the most socially excluded and vulnerable groups. They
are often subject to multiple disadvantages, experiencing very significant levels of health and social
inequality as compared to other families. Additional stressors can include domestic violence, poor

- physical or mental health, substance misuse, social isolation, poor housing, poverty, being a care leaver or having a disabled child.
- These parents are sometimes targeted by individuals who may pose a risk to children and the children could in these situations be vulnerable to abuse and neglect.
- Concerns for the children's welfare are usually based on 'neglect by omission'. The issues which most frequently give rise to concern in relation to parents with learning disabilities arise from not knowing how to meet their children's needs; a lack of skills, understanding or knowledge of the child's needs, rather than deliberate abuse.
- The ability of parents with a learning disability to provide a reasonable standard of care will depend on their own individual abilities, circumstances, the individual needs of the child and the level of support available to them.
- Parents with learning disabilities may need considerable support to develop the resources, skills, understanding and experience to meet the needs of their child.
- People with learning disability can parent their children well but many require support to do so.
 This requires all relevant services to work closely together to develop an approach based around commonly understood principles of good practice.

Parents' relationship with services

- Parents with learning disabilities often feel that professionals believe that they will not be good parents. They also feel (and some research confirms) that they are held to higher standards than other parents.
- Parents with learning disabilities are often scared to engage with services as they fear their children will be removed from their care.
- Services often face challenges to understand and meet the needs of parents with learning disabilities.

Recognition and screening of parental learning disability

It is not always clear whether a parent has a learning disability, but the following information (if available) may help its identification:

- Is there evidence of a learning disability in their medical records? Are they on the Learning Disability register or are they known to Learning Disability services?
- Is there evidence in their educational records? Did they have an Education, Health and Care Plan or attend at a special school?
- What did they do after leaving school? Have they acquired any qualifications? Did they attend a day centre? Are they in receipt of any benefits e.g. PIP?
- Do they have difficulties with literacy or numeracy? (verbal reasoning can mask this difficulty)
- Do they find complex questions frustrating and overwhelming?
- Do they see themselves as having a learning disability?
- Are they responsive do they seem to understand written communication or requests and comments made? Do they follow through on matters agreed? Are they aware of the areas with which they need help?

Services may consider further assessment to assist in their understanding of likely impact of learning disability on the parents' everyday life and parenting. These assessments will enable an appropriately

tailored support plan to be developed. These assessments may include a cognitive assessment or assessments from Speech and Language Therapists (SALT) or occupational therapist (OT) etc.

Key Principles when working with parents with a diagnosed learning disability or a milder/borderline learning disability

- Local authorities, and all other agencies working or in contact with children, have a responsibility to safeguard and promote children's welfare.
- It is the parents' responsibility to care for their child where this is in the child's best interests, and children's needs are usually best met by supporting their parents to look after them.
- The children of parents with learning disabilities should not automatically be assumed to be 'children in need' or 'at risk'.
- The needs of the child are best met when their parent's support needs, including needs arising from their parenting role, are acknowledged, assessed, facilitated and regularly reviewed.
- Early identification of parents' communication needs, including the need for an interpreter, advocate, or accessible information, is essential.
- Parents with disabilities are entitled to equal access to services, including parenting support and information services. Reasonable adjustments should be made so that services are provided in an appropriate, accessible way for these parents.
- The needs of parents with learning disabilities and family members should be established at an early stage and support should be needs-led, aim to support family and private life and to prevent unnecessary problems from arising.
- Where possible and appropriate, parents' support needs should be addressed by enabling parents
 to access universal and community services, with reasonable adjustments made to facilitate
 engagement with support on offer. Additional support needs should be met by the timely provision
 of specialist assessments and services. Support should be delivered in a non-judgemental and
 empowering way.
- A family-centred approach should be taken to parenting support, responding to the needs of all family members (including fathers), rather than just the mother or just the child.

Assessing parents' capacity to parent and their support needs

Research shows that assessments are sometimes influenced by negative stereotypes about the capacity of parents with a learning disability to parent. When problems are seen as rooted in people's personal deficits and limitations, they may seem intractable and out of reach. Shifting the focus onto features of people's lives that can and should be changed, challenges negative stereotypes.

Parents with learning disabilities are understandably concerned that involvement with statutory services may result in their child being taken into care. This fear can create barriers to conducting an accurate assessment.

A whole family, multi-agency, approach to assessment is needed as early as possible, especially in the antenatal stage. Joint assessment between all relevant agencies is beneficial and reduces duplication. A Care Act assessment may be completed alongside an assessment relating to a child, so that interrelated needs are properly captured, and the process is as efficient as possible.

Those being assessed must consent to the assessments being combined, otherwise they will be carried out separately. Thought should be given to who is the most appropriate person to conduct the assessment.

Where assessments involve more than one member of staff at the same time, care should be taken to ensure that the roles of each professional are explained and understood.

Parents should be supported and enabled to participate in assessments and decision-making and to make a meaningful contribution to meetings. (Please look at the section below on accessible communication.)

If a parent has substantial difficulty in being involved in their assessment and adaptations to the process would be insufficient to overcome this, an independent advocate must be arranged to support the person in the assessment process.

In addition to a Care Act assessment,

- a specialist parenting assessment such as ParentAssess, Cubas or PAMS should be undertaken to ascertain parents' capabilities as well as their support needs
- cognitive functioning assessment
- functional assessment (also known as living skills assessment)
- communication assessment
- psychological factors that may impact on parenting ability, e.g., loss, mental illness, emotional issues resulting from trauma, etc.

Assessments should lead to a care plan which will identify the eligible needs of parents and children and how these will be met, the cost (if any) to the service user, the source of funding, the start and finish dates of services provided and contingency plans for emergencies.

The care plan should distinguish between the assistance the parent requires to perform tasks, and the assistance that is required to help them learn new skills. Services provided by non-statutory agencies should also be recorded together with the input of any informal carer and a copy of the care plan, in an appropriate format, provided to the parents.

A more detailed document discussing assessments of parent with learning disabilities can be found here: wtpn assessment doc finalDec2014 (1).docx (live.com)

Positive practice

The key elements of positive practice are summarised in the Good Practice Guidance (WTPN 2021). See section above and <u>FINAL 2021 WTPN UPDATE OF THE GPG.pdf</u> (bristol.ac.uk).

This section includes brief information regarding:

- Relationship-based working with parents
- Accessible communication
- Supporting parents to develop parenting skills

Relationship-based working with parents

Parents are likely to need access to on-going, regular support during the different stages of their child's development so as to enable them to adapt to the child's changing needs. This support should be offered by a known and trusted individual who has built up a relationship with the parents over many years. The 6Ts practice framework (Tarleton et al., 2018) is a resource to support the development of positive relationships with parents with learning disabilities and to facilitate reasonable adjustments required under the Equality Act.

Time

Trust

Tenacity

Truthfulness

Transparency

Tailored Response

Positive practice requires workers to spend additional **time** to develop **trust** with parents. Parents are often scared to admit they need help as they feel this need for support will result in their children being removed from their care.

Working with parents requires **tenacity** to keep engaging with parents, to see issues that may occur and to develop support/strategies to avoid potential issues. Workers need to be **truthful** with parents about the issues, being very clear and concrete as to the concerns about the child/family home/way parent is engaging with their child. All the workers involved with the family need to be **transparent**, with both the parents and with other workers, about their respective roles.

The Getting Things Changed Summary Report also details three case studies of multiagency working and the 'think family' approach with parents who have a learning disability. https://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/GTC%20SUMMARY%20REPORT%2016.5.2018%20designed.pdf

Accessible information and communication

The Equality Act 2010 requires that reasonable adjustments be made to ensure that disabled people have equal access to information and advice services. Accessible information and communication have been recognised as crucial in enabling parents with learning disabilities to engage with services and to therefore maximise the chances of children's needs being met.

Parents often need more time and support to understand communications. Having a supportive relationship with a key worker – see 6Ts above – will support communication with parents. Advice can also be sought from a Speech and Language Therapist (SALT). Advocacy support may also be needed.

The professionals involved with the family should be clearly identified and communication pathways developed to facilitate a cohesive, coordinated service, that is supportive to all those involved.

Key aspects of accessible verbal communication:

- Taking more time to explain things.
- Being very concrete and direct. Using the same words repeatedly rather than using different words that mean the same thing.
- Telling parents things more than once and checking their understanding of what has been said.

When communication with parents is written:

- Sentences should be short no more than 15 words, use concrete language and no jargon. If jargon has to be included, it should be explained.
- Each point should be illustrated with a photo or illustration explaining the text. If possible, the pictures should be of the actual workers, locations, tasks being discussed. The information should be checked with the parents to ensure they understand it.

When involving parents in meetings, it is supportive to:

- Consider how the parents need to be prepared for meetings. Discuss with parents what would be helpful for them and involve their advocate in these discussions. Parents may need reminding when the meeting is, perhaps via a text message or phone call.
- Provide the meeting paperwork, in an accessible format, in advance of any meetings to enable parents to explore with their advocate or trusted person.
- Keep meetings short and have breaks.
- Consider whether a long meeting covering multiple issues should be broken down into shorter meetings that cover single issues.
- Check the parents are understanding what is being said.
- Provide the minutes of the meeting in an accessible format, perhaps written or also as an audio message on their phone that they can keep listening to.
- Consider that parents may also need reminders by phone or text regarding the timing of assessments.

An advocate can assist by supporting the parent(s) to engage more fully with professionals, assist with communication issues and support the parents to understand the expectations of others, as well as supporting the parents to understand the more complex issues arising from child protection procedures and legal action.

An advocate can also assist professionals, by identifying and addressing any misunderstandings that might arise on the professionals' part about the parent's learning disabilities.

Supporting parents to develop skills

When supporting parents to develop new skills and understanding, it should be recognised that each parent is individual, but the following strategies are helpful:

- Break down tasks into small steps, demonstrating each step and allowing additional time for each step and for repetition.
- For written instructions, a brief, concrete instruction in a short sentence, accompanied by an explanatory picture.
- Use of visual aids such as short films or props.
- Use of practical demonstrations and concrete examples.
- The parent may find it easier to learn in her/his own home to maximize transference of learned skills.

Parents can also benefit from support from parenting groups for parents with learning disabilities and from adapted parenting programmes such as Mellow Parentings' Mellow Futures (Mellow Futures | Our Programmes | Mellow Parenting).

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