

Supporting Families Where a Parent has a Learning Disability: Guidance for Social Workers

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USW Background

- Concern regarding the number of children being taken into care in Wales
- One group thought to be at particular risk of this occurring are children of parents who have a learning disability
- In 2019 Welsh Government commissioned the Institute of Public Care to undertake research looking at the number of children in Wales removed from parents with learning disabilities and the reasons behind their removal.
- Key recommendations
 - the development of an improved national definition of learning disability
 - the development of national guidance to support social workers to better identify and support families where a parent has a learning disability

USW

Project Team

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USW Methods

- Reviewed the research undertaken by The Institute of Public Care
- A scoping review of relevant research, policy and guidance
- Discussion with key stakeholders at a national and international level
- Interviews with parents with learning disabilities
- Focus groups and individual interviews with a range of stakeholders including social work managers and practitioners
- Feedback from stakeholders regarding early drafts of the document.

USW Underpinning values

- Respect for rights
- Focus on the family
- Strengths-based approach
- Early intervention and a pro-active approach

Key areas

- Identification of parents with learning disabilities
- Effective communication
- Independent advocacy
- Assessment
- Planning and delivering effective support
- Support in Court proceedings
- Collaboration, coordination and continuity
- Organisational support

Good practice points identified in each area

Identifying Parents with Learning Disabilities

‘The first social worker never really knew that I had a learning disability and the second social worker found out, and has been really understanding, takes a lot more time to speak to me and gives me more time to try to understand stuff’ (Parent 4)

Good Practice Points

- If the parent has a confirmed learning disability, this should inform subsequent family assessment and the provision of support.
- Where a parent presents as having a learning disability, but does not have a diagnosis and/ or is not known to the Adult Community Learning Disability Team, then (with the parent’s consent) use of a screening tool should be considered.
- The provision of appropriate support should not be delayed until a formal diagnosis/ assessment is obtained. The guidance included in this document should be applied whenever a parent presents as having a possible learning disability.

Effective Communication

“The best thing about what she does is to reassure you and support you, she yeah, she never judged me and my husband and said she knew where we were coming from... The best thing was she was always upfront and honest, she literally told us what was going on’ (Parent 13)

Good Practice Points

- Ask the parents how they wish to be communicated with and agree how communication will be achieved. Ask ‘what works best for you?’
- Ensure that you ‘listen’ not only to what is said but also to what is communicated through body language, facial expression etc.
- Give parents ‘permission’ to express views by actively seeking their opinions and checking if there is anything that they wish to say.
- Avoid the use of ‘jargon’ where possible and (where this is unavoidable) ensure that a plain language explanation is given (See Appendix 2 for some resources)
- Provide information in formats that support parents to understand and retain it. This might include providing information in Easy Read format, the use of signing or symbols, providing audio recordings.
- Pay attention to the quantity of information provided at any one time and the pace it to promote understanding and to avoid information overload.
- Check understanding of information provided - both your understanding of what the parents have said and the parents’ understanding of what has been said to them.
- Check retention of information – for example checking at each visit what was discussed at the last.
- Provide support to assist parents with retaining and acting on information such as sending reminder texts or phone calls, using pictorial information etc.

‘Well, my son moved school and his behaviour was bad then they started coming in more. He was difficult in school and at home. I think they should have been more involved instead of just meetings, at the beginning I did not know what was going on but then I got an advocate and they helped me a lot. ‘ (Parent 8)

Good Practice Points

- Parents with a learning disability should be made aware of independent advocacy services at the earliest opportunity and supported to access them if they wish.
- Independent advocates should have both experience of working with people with a learning disability and experience and understanding of child protection proceedings.
- Independent advocates should be involved as soon as possible to ensure parents receive support during assessment and any subsequent court proceedings. It is not acceptable for parents to meet an advocate for the first time immediately before entering a court.
- Independent advocates should work with parents with a learning disability over a period to promote continuity, greater understanding of the parents’ strengths and wishes, and to promote the trust required for an effective advocacy relationship.
- It is essential that specialist independent advocacy services for parents with a learning disability are available and funded.

“All her life I have told professionals that there is something not right, but I was always blamed...It turns out that [name of daughter] has a genetic condition, which means she has a learning disability ... I have told every single social worker about this but they never listened to me. ... Always told bad parenting. I have been fighting since she was 3 years of age. ‘(Parent 2)

‘The only thing was the PAMS assessment, and that was not suitable for me. it was trying to do things within a time, and they didn’t change the time for me. and then the advocate fought for extra time for me. the social workers are under strict time scales. They used to say stuff and I was like “what are you on about?” ‘(Parent 8)

Good Practice Points

- Take time to build a relationship with the family before starting the assessment process
- Ensure that the assessor has the right knowledge and skills to undertake the assessment. This should include experience of working with adults with a learning disability.
- Consider developing an agreement/ ground rules with parents as to how the assessment will be conducted. Make sure the parents have a copy, that it is easily understood by them, and that it is regularly revisited.
- In keeping with the Social Services and Well-being (Wales) Act (2014)⁴ ensure that the starting point for assessment is to ask the parents ‘What matters for you?’
- Ensure that the assessment is based on the family’s existing strengths and supports

Planning & Delivering Effective Support

'I just want to get them to start bringing in people to help parents with learning disabilities, I know it costs money, but money should not be considered. It should be like Flying Start, so the parents are helped and taught the skills they need before the child is born and (before) it even goes to court. Do it early on. The funds need to go on the right channels.' (Parent 6)

'Then the midwife taught me when I came home to do bottles and feeding. I asked her to show me how to do things. She was there all day, and she taught me how to sterilise ... I had all the support that I needed, but I think I needed that little bit of help.' (Parent 9)

'The health visitor would come out and say right breast feed. Do this. Do that and then leave. You know tell you what to do, but not necessarily how to do it. We didn't have a clue.' (Parent 12)

Good Practice Points

- Ensuring the plan is produced in an easy read format which is then talked through with the parents to ensure understanding
- Breaking down the plan into smaller sections that can be understood one part at a time
- Providing an audio recording of the plan that the parent can listen to several times
- Ensuring that an independent advocate is available to assist the parent with contributing to and understanding the plan
- Ensuring that prompts / reminders are provided when specific timescales must be met – these might include (for example) text reminders and visual calendars
- Providing reminders to assist with memory when key actions are required within the home setting. For example, rather than saying that a feed requires 200 mls of fluid provide a cup that measures the required amount and tell them to use that cup to measure.
- Including photographs of key people in a plan to provide a helpful reminder of who does what.

Support in Court Proceedings

'when you go into a complicated court process and not even the social workers like understand half the time... so imagine the stress of thinking, oh, if I don't get this right, I'm gonna lose my child. They just don't say anything. You know you're offering me solicitor 10 minutes before you get these huge documents' [Parent 12]

Good Practice Points

- Parents should receive support to prepare for court to understand what will happen
- If the parents wish, they should receive support to develop a statement of their views and wishes that can be submitted to the court
- During court proceedings moral and communication support may be required along with adjustments to proceedings.
- Following court parents may require support to understand the outcomes and their implications. Where children are removed then they should also be reassured regarding their children's welfare.
- An independent advocate who has an established relationship with the family and who has experience of supporting people with a learning disability can be vital in providing support throughout and following the court process.

Collaboration, Coordination and Continuity

‘Social Workers need people working with the community learning disability team a bit more, to get the full picture of which needs need to be put in to place. Cos at the moment, it is not working. Too many people are falling through the gaps, with no support.’ (Parent 6)

Good Practice Points

- A clear and coordinated approach to care and support is required for families where a parent has a learning disability to ensure they can access the most appropriate knowledge, skills, and support.
- Coordination needs to occur both within the local authority and between agencies (both statutory and third sector)
- The impact of staff changes on parents needs to be acknowledged and where possible minimised.

Organisation Supports

‘Social Workers need people working with the community learning disability team a bit more, to get the full picture of which needs need to be put in to place. Cos at the moment, it is not working. Too many people are falling through the gaps, with no support.’ (Parent 6)

Good Practice Points

- A clear and coordinated protocol for joint working to identify and support parents with a learning disability should be in place in each local authority. This should include identification of how independent advocacy will be provided and where financial responsibility for the provision of care and support lies.
- Social work practitioners should be provided with education and training in relation to supporting parents with a learning disability. This should include communication skills and the importance of making reasonable adjustments.
- Assessment of parenting capacity should be undertaken by practitioners who have experience of working with adults with a learning disability and who are appropriately trained to use the assessment tool.
- Local authorities should ensure that resources such as a learning disability lead/ champion and information regarding local learning disability services are easily accessible to practitioners in children’s services.

Whilst the guidance is targeted at practitioners a number of organisational and structural issues have also been identified and raised. These include:

- The need to ensure appropriate education regarding the needs of people with learning disabilities (including specifically focused on parents with learning disabilities) for all social workers
- The need to ensure that child and family teams work in partnership with adults with learning disabilities teams to ensure appropriate expertise is utilised
- The need to ensure that there is access to independent advocates with both learning disability and child protection expertise at an early stage and that this provision is adequately funded

ANY
QUESTIONS
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