Newborn babies | January 2025

What are the experiences of parents with learning disabilities or difficulties in care proceedings?

Nuffield
Family Justice
Observatory

Spotlight

Introduction

Parents with learning disabilities/difficulties are over-represented in child protection processes and care proceedings and in experiencing the permanent removal of their children (Booth et al. 2005). Several recent research studies have provided a timely reminder of the challenges these parents face. Their findings paint a concerning picture of the experiences of parents with learning disabilities and indicate that the family justice and social care systems are paying insufficient attention to ensuring that their rights under disability, equality and human rights legislation are upheld.

This Spotlight paper brings together the main messages from:

- *Babies in care proceedings: What do we know about parents with learning disabilities or difficulties?* Burch et al. (2024)
- *Substituted parenting: What does this mean for parents with learning disabilities in the family court context?* Tilbury and Tarleton (2023)
- *The role of adult social care for parents with learning disabilities when their children are no longer in their care.* Baginsky (in press)
- *How do adult and learning disability social workers engage with parents with learning disabilities?* Tarleton et al. (2024)
- *Research on the number of children in Wales placed into care from parents with learning disability and the reasons behind their removal.* Burch et al. (2019)

Terminology can cause confusion – learning disabilities or learning difficulties?

There are distinct definitions for learning disability and learning difficulty.

Learning disability is defined as: 'A significantly reduced ability to understand new or complex information, to learn new skills, with a reduced ability to cope independently, which started before adulthood' (Public Health England 2023).

Learning difficulty is defined as: 'A reduced intellectual ability for a specific form of learning ... includes conditions such as dyslexia (reading), dyspraxia (affecting physical coordination) and attention deficit hyperactivity disorder (ADHD)' (Public Health England 2023).

There is no reference to IQ levels in the definition of learning disability, but psychologists, when called on to determine whether an adult has a learning disability, will include IQ testing within a broader clinical assessment. An overall IQ score of less than 70 is considered an indicator – not a predictor – of learning disability (The British Psychological Society 2015). The broader clinical assessment will look at a range of different aspects of cognitive functioning.

Tarleton et al. (2024) note that local authority adult learning disability services in England commonly assess eligibility for their services by using IQ levels below 70. This excludes parents who would otherwise meet the definition of having a learning disability and who may struggle with their day-to-day life and role as a parent in the same way as parents who have been accepted for adult learning disability services. Tilbury and Tarleton (2023) use the term 'parents with LD' to include this broader group of parents and Burch et al. (2024) use 'parents with learning disabilities or difficulties' in the same way. In this paper we use 'parents with learning disabilities/difficulties' in this way as well, except when findings relate to studies that did not use this terminology.

Key messages

1. A high proportion of care proceedings concerning babies involve parents with learning disabilities/ difficulties

Burch et al. (2024) found that in one third (34%) of the 200 most recently concluded care proceedings concerning babies in 4 local authorities, there was reliable evidence that one or more of the parents involved had learning disabilities/difficulties. This prevalence varied by local authority area (from 44% in a county area to 22% in a London borough).

Evidence of learning disability/ difficulties was identified through examination of children's services and court files, in the main through cognitive assessments ordered once the case was in court. These assessments usually provided IQ indicators, presented alongside other more in-depth information about the nature of parents' difficulties. Just under half the parents had IQ levels of below 70 and a similar number had IQ levels between 70 and 80 combined with significant difficulties in relation to parenting tasks. A very small proportion of parents had specific learning difficulties (mostly ADHD) alongside a low average overall IQ and difficulties with parenting tasks. Thus, in a large proportion of the positively identified cases, parents' overall IQ scores were an indicator of either learning disabilities or borderline learning disabilities, which could also be described as 'parents with LD' if following the suggestion by Tilbury and Tarleton (2023).

Reflection

Do you know how many care cases in your court or local authority involve parents with learning disabilities/ difficulties?

Do you know how many parents with learning disabilities/difficulties are involved with children's social care in your area?

How would you find this information?

Do you have processes and systems in place to accurately record this data?

2. Late identification of learning disabilities/ difficulties means that assessments and interventions are unlikely to be tailored to parents' learning needs

Burch et al. (2024) found that in around three-quarters of cases (75%) parents' learning disability/ difficulty had not been identified until their cases reached court. Tarleton et al. (2024) and Burch et al. (2019) also found that there were delays in identifying learning disability before court proceedings.

Late identification of parental learning disabilities/difficulties means that key parenting assessments and interventions are unlikely to be tailored to parents' learning needs, making meaningful engagement less likely. It also means that important decision-making processes – such as child protection case conferences, formal pre-proceedings meetings and initial care proceedings hearings – are not tailored to parents' needs, with a strong risk then that parents do not fully understand what is happening and what the implications are. If adaptations are not being made to meet the needs of people with learning disabilities/difficulties, there is potential for serious injustice.

Burch et al. (2024) noted that cognitive or intermediary assessments completed once cases were in proceedings were likely to result in adjustments being made to the way in which the proceedings were managed, but as this was often towards the end of proceedings these adjustments only affected final hearings. Sometimes a cognitive assessment would lead to a case being adjourned so that appropriately adjusted parenting assessments could take place, but this was often too late to allow the parents a proper opportunity to demonstrate their capacity to parent because of concerns about timescales for decisions about babies as well as pressure to complete cases within a tight timescale.

A number of specialist parenting assessment frameworks for use with parents with learning disabilities/ difficulties are available. Ideally, and particularly in pre-birth cases, the assessment process should begin as early as possible to ensure that parents are given the best opportunity to understand the concerns of the local authority and for the appropriate services, support and interventions to be provided for them and their children. Burch et al. (2024) found that specialist assessment frameworks were not always used as intended, and that once cases were in court, a lack of understanding of the methodology involved in the different frameworks could lead to insufficient questioning of the evidence underpinning the conclusions of the assessment.[1]

In relation to the process and experience of care proceedings, both Burch et al. (2024) and Baginsky (in press) recommend that a problem-solving court process similar to that of the Family Drug and Alcohol Court (FDAC) would provide a fairer and more humane court experience for parents with learning disabilities.

Reflections

Is it common in your experience for learning disabilities/difficulties to be identified once proceedings have started?

Have you found that appropriate adjustments to services and tailored support for parents have been delayed by late identification of learning disabilities/difficulties?

Have you been concerned about the fairness of hearings following late identification of learning disability/ difficulties?

How familiar are you with the parenting assessment frameworks used for parents with learning disabilities/ difficulties?

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[1] See slides with accompanying audio explanation by Nadine Tilbury on assessment frameworks, at: youtu.be/2AOIeDpJ6PE

3. Reasons for late identification of learning disabilities/difficulties include a lack of confidence and experience among social workers, time pressures and delays in obtaining specialist assessments

Burch et al. (2024) identified a number of reasons for the late identification of parental learning disabilities/difficulties, including children's social workers not screening effectively for learning disability because they did not have the right training or experience, they did not have access to screening tools or because work pressures meant they were not able to spend sufficient time talking face to face with parents.

Shortage of time was a particular issue in those cases (81% in the Burch et al. 2024 study) where parents were referred to children's social care in pregnancy. In such circumstances the researchers found that although referrals were commonly made in the first and second trimester of pregnancy, parenting assessments and relevant interventions were not started until much closer to the birth of the baby and the issuing of proceedings. This creates further injustice because of the very short period of time available for parents to demonstrate their parenting capacity. This can affect all parents in cases involving care proceedings immediately post-birth but parents with learning disabilities/difficulties are at particular disadvantage. Burch et al. (2024) noted that following the *Born into Care* best practice guidance (Mason et al. 2023) would ensure much earlier assessment and intervention in pre-birth cases.

In addition, Burch et al. (2024) highlighted that there were usually other areas of professional concern when babies become the subject of care proceedings, in particular parental mental health, parental substance misuse, domestic abuse, or parental vulnerability to exploitation in the community. Some interviewees thought these other factors made it harder to identify or focus on parental learning disability/difficulties because they pose a more obvious immediate risk to children.

Finally, Burch et al. (2024) identified that there were concerns within local authorities about the cost of specialist parenting or cognitive assessments and potential delays arising from a shortage of professionals to complete them. Combined with these concerns was an expectation that specialist assessments would be ordered and commissioned once care proceedings had started.

Burch et al. (2024), Baginsky (in press) and Tarleton et al. (2024) all note that the existing guidance on working with parents with learning disabilities – Good Practice Guidance on Working with Parents with a Learning Disability (Working Together with Parents Network 2021) – despite being regularly recommended by judges, is not widely followed or even known about. This guidance recommends timely and in-depth assessments, with appropriate involvement from both children's and adult services. Baginsky (in press) recommends a review, refresh and reissuing of the guidance by the relevant government departments in England. In Wales, following the publication of research by Burch et al. (2019), government guidance was published on working with parents with a learning disability (Welsh Government 2023).

Good practice: Durham's pre-birth intervention service

Durham has had a pre-birth intervention service since 2004. It now has three pathways, one of which is for parents with learning disabilities/difficulties. Work will start with parents as early as possible, eight to ten weeks into the pregnancy. Many of the workers in the service are trained in ParentAssess, one of the specialist parenting assessment frameworks for parents with learning disabilities/difficulties. They use early screening tools with parents and adjust all interventions as necessary. They use pictorial and other methods with parents and check their understanding throughout. Early screening also means they can organise timely cognitive assessments to inform interventions with parents. They aim to have a clear plan for the future by 30 weeks. If care proceedings seem likely, they start formal pre-proceedings early to ensure that parents can have legal advice from that point.

Early identification of parents' learning disabilities/difficulties and reasonable adjustments being applied earlier should increase access to appropriate support, ultimately affecting how well parents can engage in care proceedings and helping to ensure a fair court process in line with Article 6 of the European Convention on Human Rights.

Reflection

Are you aware of, and do you make use of, the *Born into Care* best practice guidelines (www.nuffieldfjo.org.uk/resource/born-into-care-best-practice-guidelines-and-other-resources)?

Are you aware of, and do you make use of, the Working Together with Parents Network good practice guidance (www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/final%202021%20wtpn%20update%20of%20the%20gpg.pdf)?

What training is available for children's social workers on working with parents with learning disabilities/difficulties?

4. Insufficient communication, coordination and understanding across adult and children's social care impacts negatively on ensuring appropriate support for parents with learning disabilities/difficulties

Under the Equality Act 2010, public sector organisations must make adjustments to ensure that support and services are equally available to people with disabilities and those without. Under section 6 of the Act a disability includes mental impairment which has a substantial and long-term adverse effect on a persons' ability to carry out normal day-to-day activities.

All the studies identify patchy provision of reasonable adjustments for parents with learning disabilities/difficulties, often linked to late identification of these disabilities/difficulties.

The Care Act 2014 is the gateway to accessing adult social care services and section 9 places a duty on local authorities to assess a person's needs if it appears they may need care and support, regardless of the local authority's view on the level of those needs. Eligibility criteria for Care Act support are set out in the Care and Support (Eligibility Criteria) Regulations 2015 and are broad: needs arising from a mental impairment that mean a person cannot achieve two of ten outcomes, one of which relates to parenting. Burch et al. (2024) identified a lack of knowledge and understanding about the Care Act among children's social workers, which impacts on their ability to advocate for an assessment on behalf of parents. Burch et al. (2019 and 2024), Tarleton et al. (2024) and Baginsky (in press) comment on delays in obtaining assessments and high thresholds for accessing services applied locally. In the Burch et al. (2024) study, adult social care support was requested in just over a quarter of cases (27%) and provided in 15% of cases.

Baginsky (in press) and Tarleton et al. (2024) explored the role played by adult social care services in providing support for parents with learning disabilities and the links between adult and children's social care. Their findings are similar and include:

- within most local authorities, there is little connection between adult and children's social care
- there is a lack of understanding of each other's processes – adult social workers often do not understand child protection processes, thresholds for intervention and timescales, while children's social workers lack understanding of the Care Act 2014 and how that can be used to support the parents they are working with
- where adult social care was already involved with a parent, there was evidence that they were not always invited to child protection conferences or kept up to date with planning within children's social care
- when children's social care is involved with families, adult social care practitioners can assume their involvement is not needed
- social workers in children's or adult social care can have mistaken expectations of what each other can provide to support parents
- social workers in generic adult social care teams, as opposed to those in specialist learning disability teams, lack experience and confidence in working with parents with learning disabilities.

Pockets of good practice were identified by Baginsky (in press) and Tarleton et al. (2024), often where a dedicated learning disability team was embedded in adult social care, or where there was a learning disability team working across children's and adult services. Elsewhere, it was often the commitment of individual adult or children's social workers that led them to argue for resources or to build contact with each other and with other agencies.

Social worker communications with parents are key to ensuring engagement and participation. All the researchers identified examples of good quality communication, tailored to parents with learning disabilities/difficulties. However, evidence suggests that the quality of this key aspect of social work practice is very variable. Professional interviewees suggested that the main reasons for this included a lack of adequate training, confidence and insufficient time to put theory into practice.

Good practice: Published guidance and principles

Good Practice Guidance on Working with Parents with a Learning Disability (Working Together with Parents Network 2021) sets out five key features of good practice in working with parents with learning disabilities/ difficulties:

- accessible information and communication
- clear and coordinated referral and assessment processes and eligibility criteria
- support designed to meet the needs of parents and children based on assessment of their needs and strengths
- long-term support, if necessary
- access to independent advocacy.

Burch et al. (2024) identify the following principles of good practice in making adjustments for parents with learning disabilities/ difficulties:

- early exploration of parents' communication preferences and development of a communication plan or 'passport' that could be shared with a range of professionals
- allowing for more time and explanations
- greater use of face-to-face conversations and simple sentences
- providing reminders of information (in writing or visually) after key conversations, for parents to refer to between visits or sessional support
- being aware of attention spans and the potential need for breaks in a conversation or meeting
- use of visual tools (e.g. a trauma-informed patchwork quilt) in direct work
- accessible summaries of assessments
- easy-read, accessible information about the formal pre-proceedings process – this was available in one local authority only.

See: www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/final%202021%20wtpn%20update%20of%20the%20gpg.pdf

Reflections

How familiar are you with the provisions of the Equality Act 2010?

How familiar are you with the provisions of the Care Act 2014?

What training is available for adult social workers on working with parents with learning disabilities/difficulties?

How well coordinated are children's and adult services in your area?

5. Advocates and intermediaries have an important role to play in enabling parents with learning disabilities/difficulties to engage fully in meetings and court proceedings

Burch et al. (2024) and Tilbury and Tarleton (2023) note that support from advocates and/or intermediaries with the skills to work with parents with learning disabilities/difficulties can make a real difference to parents' ability to understand the concerns of the local authority, to navigate local services, and to understand the legal process in pre-proceedings and in court.

They also note that access to support in this way is limited. Advocacy services are not consistently available in all areas, and where they are, there are often long waiting lists. There was also evidence that not all advocates have the knowledge or experience to support parents with learning disabilities/difficulties. Funding for such services can also be lacking.

As a vulnerable party, a parent with learning disabilities/difficulties could potentially have access to a lay advocate and/or an intermediary in court to help with communication and improve their understanding and participation. Burch et al. (2024) and Tilbury and Tarleton (2023) noted that parents and professionals taking part in the research thought jargon was used too frequently, making it difficult for parents to understand what was happening without such support. Other adjustments for parents with learning disabilities/difficulties might include support when giving evidence and being cross-examined, regular breaks and use of a designated room. These measures can help parents communicate why their baby should remain in their care, or better understand why their child is to be separated from them if that is the court's final decision.

Intermediaries tended to be involved only when cases were already in proceedings. This meant their assistance to the parents and their advice to the judge and legal and social work professionals about the specific needs of the parents in relation to understanding and communication were only available late in proceedings. Evidence from parents and professionals indicates how helpful assistance from intermediaries can be – not just in the courtroom but in meetings outside court and in preparing parents for taking part in hearings. Professionals highlight how helpful it would be to have that assistance at an earlier stage.

Burch et al. (2024) found that parents were offered a lay advocate for court proceedings in around a fifth (21%) of cases. In some instances, it was the lay advocate who had already supported parents in pre-proceedings. There was considerable variation in this practice across local authority sites. Court intermediary support was offered in 27% of cases, although this tended to be towards the end of care proceedings after a cognitive assessment had identified or clarified parents' learning needs.

Reflections

Are lay advocates for parents with learning disabilities/difficulties available in your area?

Are parents with learning disabilities/difficulties offered advocacy support when attending child protection or pre-proceedings meetings?

How well are parents supported in court in your experience?

Are intermediaries often appointed in cases you are involved in?

6. The term 'substituted parenting' is unclear and unhelpful

Many parents with learning disabilities/difficulties will need long-term support to help them parent their children, in the same way that parents with physical disabilities can also need long-term support. Tilbury and Tarleton (2023) investigated how the term 'substituted parenting' was being used in care proceedings because, although it was unclear how this term had originated, published judgments indicated that use of this term appeared to result in children being removed from their parents.

Interviews with parents indicated that they recognised their need for support and welcomed it, but were clear that they wanted this support to help them parent, not to replace them as parents. Professionals confirmed that there was no clear understanding of when support became 'substituted parenting', but that it applied when parents needed a high level of support and it was assumed that social workers or other professionals would be 'doing the parenting' and hence children would develop problems with attachment, which would significantly harm their welfare. However, the research found that where it was argued that the support needed amounted to 'substituted parenting', there was no analysis of the perceived risks that were feared might arise from a high level of support, nor was any thought given to how these risks might be addressed, managed or even eliminated.

The report calls for a detailed analysis of the perceived risks of long-term support and how these might be addressed in every case involving a parent with learning disabilities/difficulties. It includes a template for this analysis of risk (Appendix 1, p. 41). When children are being removed from their families in consequence of a court agreeing that the support proposed would amount to 'substituted parenting', it is important to know that any arguments being raised against providing support are legitimate and are not based on cost, prejudice or other inappropriate factors. The current lack of this analysis raises concerns around the fairness and transparency of the family court system in relation to cases involving parents with learning disabilities/difficulties.

The researchers point out that parents with learning disabilities/difficulties are not unusual in needing ongoing or recurrent support with their parenting.

Reflection

What is your understanding of 'substituted parenting'?

Are you satisfied that there is always a detailed analysis of any support plan and any potential risks arising from this, in cases where concerns about 'substituted parenting' have been raised?

7. There is need for post-proceedings support for parents with learning disabilities/difficulties who lose their children through care proceedings

Burch et al. (2024) and Baginsky (in press) comment on the lack of support for parents once proceedings come to an end. Recommendations made in court reports for therapeutic or psychological interventions with parents are rarely followed through. Difficulties parents have experienced in accessing learning disability or mental health specialist services before losing their children continue post proceedings. The findings about parents' experiences mirror findings from research into recurrent care proceedings and the impact of the removal of a baby on parents (Alrouh et al. 2022; Ryan 2021).

Some areas do have specialist recurrent care services (Mason and Wilkinson 2021) and where parents with learning disabilities/difficulties are able to access these, they are positive about the support they receive. Many areas still do not have such provision, and where services do exist, they are often small with necessarily limited capacity for meeting the needs of all relevant parents in their area.

Providing post-proceedings support to parents who have experienced removal is important, as Burch et al. found that nearly half (49%) of the mothers and 28% of the fathers in their study had previously had children removed through proceedings.

Reflection

Is there a service to support recurrent care parents in your area?

If there is a service, does it provide support to parents with learning disabilities/difficulties who have had a child removed through care proceedings?

Resources

The Working Together with Parents Network (based at the University of Bristol) has made a film for parents and professionals linked to the 'Substituted Parenting' research, presenting parents' views and examples of positive and negative support: www.bristol.ac.uk/sps/wtpn/substituted-parenting

Nicola Lewis, intermediary, talking about the work of intermediaries (scroll down to clip): www.nuffieldfjo.org.uk/resource/babies-in-care-proceedings-what-do-we-know-about-parents-with-learning-disabilities-or-difficulties

Jessica Hurst, solicitor, talking about her role and use of lay advocates and intermediaries (scroll down to clip): www.nuffieldfjo.org.uk/resource/babies-in-care-proceedings-what-do-we-know-about-parents-with-learning-disabilities-or-difficulties

Mary Baginsky, Pause (Southwark) and Mencap Cymru have produced an animation for social workers: www.youtube.com/watch?v=dyljEGcFYnY

Mary Baginsky; Mencap Cymru; Celestine Greenwood, a barrister in Exchange Chambers; and Amy Harrison, an independent intermediary have produced an animation aimed at lawyers: https://youtu.be/mdsycNK93kY

Nadine Tilbury. PowerPoint presentations covering:

- a general overview of parents with learning disabilities or difficulties in care proceedings (https://youtu.be/S0ipEUJq-9U)
- parenting assessments – content and questions to ask (https://youtu.be/2AOleDpJ6PE)
- substituted parenting (https://youtu.be/b7Fw3WCTLZ8).

Nadine Tilbury (2023). *Example template for analysis of risk and options to address risk.* Appendix 1, p. 41 in *Substituted Parenting*. Nuffield Family Justice Observatory. www.nuffieldfoundation.org/wp-content/uploads/2021/10/Substituted-parenting-What-does-this-mean-for-parents-with-learning-disabilities-in-the-family-court-context.pdf

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About Nuffield Family Justice Observatory

Nuffield Family Justice Observatory (Nuffield FJO) aims to support the best possible decisions for children by improving the use of data and research evidence in the family justice system in England and Wales. Covering both public and private law, Nuffield FJO provides accessible analysis and research for professionals working in the family courts.

Nuffield FJO was established by the Nuffield Foundation, an independent charitable trust with a mission to advance social well-being. The Foundation funds research that informs social policy, primarily in education, welfare, and justice. It also funds student programmes for young people to develop skills and confidence in quantitative and scientific methods. The Nuffield Foundation is the founder and co-funder of the Ada Lovelace Institute and the Nuffield Council on Bioethics. Nuffield FJO funded the development of this briefing paper. Any views expressed are not necessarily those of Nuffield FJO or the Nuffield Foundation.

This paper was written by Mary Ryan.

Recommended citation:

Ryan, M. (2024). *What are the experiences of parents with learning disabilities or difficulties in care proceedings?* Nuffield Family Justice Observatory. https://www.nuffieldfjo.org.uk/resource/what-are-the-experiences-of-parents-with-learning-disabilities-or-difficulties-in-care-proceedings

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