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Disabled Children's Social Care – Briefing #2

Families' experiences of social care

About this briefing

This is one of a series of briefings written by the Council for Disabled Children and Research in Practice. These have been developed to help practice leaders and service managers promote greater understanding across the children's workforce of the complex and often confusing legal and policy landscape around disabled children's social care.

They accompany the resource **Using a needs-led eligibility framework to provide services to disabled children and families** (June 2024).

Background

Local authorities' duties to disabled children and their families are set out in several overlapping pieces of legislation, some dating back more than 50 years (see Briefing #1 'The Law Commission's review). This has created widespread confusion among both practitioners and families around the provision of social care support for disabled children and their families.

In particular, the interaction between the *Children Act 1989*, the *Chronically Sick and Disabled Persons Act* 1970, the *Children and Families Act* 2014 and the *Care Act* 2014 makes it challenging for local authorities to meet their obligations.

Families' experiences

For many families of disabled children, 'the social care system is one of baffling complexity' (Broach & Clements, 2020, p. 84). The Independent Review of Children's Social Care (IRCSC) heard of parents' frustration at trying to navigate the system (MacAlister, 2021, p. 29), which researchers have identified as a 'key stress' for families (Cullen & Lindsay, 2019). The IRCSC highlighted the many reports it had received from parents who were struggling to access the right support when they need it (MacAlister, 2022, p. 59). Similar findings have been reported in other studies.

These findings are key to understanding local tensions that commonly arise between disabled children's families and social care. They spell out the very real day-to-day consequences for families of confused or inconsistent practice that can arise as a direct result of the complex legal framework currently governing disabled children's social care.

For example:

- **Difficulties getting an assessment:** As children in need, disabled children are entitled to an assessment of their needs. Yet more than one in four families surveyed by the Disabled Children's Partnership had been refused a social care assessment on the grounds that their disabled child 'did not meet the threshold' (Disabled Children's Partnership, 2023, p. 17). The IRCSC was consistently told by families that support was only offered once a family 'reached crisis point' (MacAlister, 2021, p. 29).
- **Lack of transparency about service provision and eligibility criteria:** Families report a lack of information about where to find help – and even when information is available, it is often inaccessible or difficult to follow (Bennett, 2016, p. 6). Many parents highlight their own 'lack of awareness or understanding of the assessment process' and the difficulties they have experienced in trying to access accurate information about eligibility criteria (Bennett et al., 2016, p. 13, p. 16).
- **Variations in support relating to assessor's expertise:** Clements and Aiello (2021) found that families' experience of assessment and support can vary dramatically according to the role and expertise of the social care practitioner undertaking the assessment.
    - An assessment by a practitioner from a disabled children's team, who has 'expertise and practice experience' of supporting the specific needs of disabled children, could lead to 'excellent support'.
    - An assessment by a 'generic' practitioner from a 'child in need team' is more likely to lead 'at best' to short-term support 'focused on addressing perceived parental failings'. Families may be denied the possibility of other support, such as direct payments, longer-term respite care or parent carer needs assessments. (Clements & Aiello, 2021, pp. 8–9)
- **An inappropriate assessment process:** For many families, the assessment process itself is long drawn-out (Bennett et al., 2016, p. 16), stigmatising (p. 13), overly 'intrusive' and 'intimidating' (Clements & Aiello, 2021, p. 5). As the IRCSC heard, the focus on safeguarding in government guidance for supporting children 'in need' is a particular source of strong resentment for families of disabled children.[1]

    > *Families with disabled children feeling that they are navigating a system that is set up for child protection, not support, has been a consistent theme in what the review has heard so far.* (MacAlister, 2021, p. 29)

    According to Clements and Aiello, national and local social care policies 'create a default position' for assessing disabled children's needs 'that assumes parental failings' – a phenomenon which the authors call 'institutionalising parent-carer blame' (Clements & Aiello, 2021, p. 4).
- **Multiple assessments:** Families of disabled children are likely to experience multiple assessments to access different services. Parents highlight 'the exhaustion of having to attend a myriad of meetings with professionals where the same information must be repeated again and again' (Clements & Aiello, 2023, p. 3).

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[1] In December 2023, the government published a revised version of its statutory guidance Working together to safeguard children (Department for Education, 2023b). A theme that 'came through strongly' during consultation was 'the importance of practitioners having knowledge and understanding of disabilities' (Department for Education, 2023a, p. 46). Many parents of disabled children described the assessment process as 'not fit for purpose' because of its focus on safeguarding rather than 'genuine practical support' to meet families' needs (p. 46). But 'other respondents highlighted the vulnerability of disabled children and the need to ensure practitioners continued to adopt a safeguarding lens when appropriate' (p. 46). The revised guidance emphasises that when undertaking an assessment, 'practitioners should recognise the additional pressures' on a disabled child's family and 'the distinct challenges they may have had to negotiate as a result of their child's disability' (p. 65).

What children say

Children and young people who took part in the Council for Disabled Children's 'Transforming culture and practice in assessment for disabled children' project also reported dissatisfaction with their experiences of the assessment process. Children and young people wanted to be involved in their assessments (Bennett, 2016, p. 16). However:

- Children and young people were often not aware that they were being assessed or what the purpose of an assessment was.
- Assessments were commonly experienced as 'intrusive' – in particular, observations could make young people feel that they were being 'watched and judged'. Children also reported feeling anxious about an outcome or decision before the assessment.
- Children and young people often couldn't see how their views had been reflected in formal reports and plans. (Bennett, 2016, p. 6; Bennett et al., 2016, p. 16)

Key points

- Parents of disabled children report difficulties getting their child and family's needs assessed, a lack of clear information about what support is available locally or how to get it, and a lack of transparency about the eligibility criteria for that support. A frequent complaint is that help is only offered once a family reaches crisis point.
- Many parents and carers of disabled children report being given incorrect information – for example, that because their child is disabled they're not entitled to early help, or that they're not entitled to an assessment of their needs.
- Families of disabled children commonly experience social care assessments as insensitive, intrusive and stigmatising. In particular, families say that the focus on safeguarding in guidance on support for children in need is inappropriate for disabled children. This is a source of considerable anger and resentment.

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