

Equal access to hospital care for children with learning disabilities and their families: a mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language that may offend some readers.

Plain English summary

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Background

There have been widespread concerns about differences in the quality of health care provided to adults with learning disability, and we do not know whether or not these differences also exist for children with learning disability. In addition, we lack an understanding of whether parents of children with learning disability and parents of children without learning disability have the same or different experiences of being in hospital with their child. The views and experiences of children with learning disability are almost non-existent in the literature.

Aims

We wanted to:

- identify the cross-organisational, organisational and individual factors in NHS hospitals that *facilitate* and *prevent* children with learning disability and their families receiving equal access to high-quality care and services
- develop guidance for NHS trusts.

Methods

The study had four phases and involved data collection in 24 hospitals in England in phase 1, including all 15 children's hospitals, and seven of these hospitals in phases 2–4. In phase 1 we carried out interviews with 65 staff, and a staff survey was returned by 2261 hospital staff.

Phase 2 included interviews and photography with 63 children and their parents, alongside a parent hospital diary and a record of any safety concerns. We also interviewed 98 hospital staff and surveyed 429 community staff. During phase 3, a satisfaction survey was returned by 812 parents and 803 children. We analysed all data according to the method we used.

Findings

Staff are struggling to tailor care to the individual needs of children. This most greatly affects those with the greatest need for individualisation, namely children with learning disability. Well-meaning staff are being let down by an inadequate system and the negative attitudes and views of the minority, which can have a lasting impact on families.

Implications for practice

We have developed a model for practice and guidelines for staff about what factors to consider when making reasonable adjustments for children with learning disability.

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