

# 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.

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## Scientific summary

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# Scientific summary

## Background

Although there is comprehensive evidence of health inequalities for adults with learning disability, including poor practice, discrimination and abuse in hospitals, to our knowledge there has not yet been a comprehensive review of how well hospital services meet the needs of children and young people (hereafter referred to as children) with learning disability and their families. A major uncertainty is when the inequalities that are known to exist for adults with learning disability start to emerge. Limited qualitative evidence of parental dissatisfaction with the quality, safety and accessibility of hospital care for children with learning disability exists. However, most of this evidence arises from small studies that focus on the views of particular stakeholders, such as children, parents or staff, and not on how services are delivered within and across particular hospital settings. The extent to which the experiences of parents of children with learning disability differ from those of parents of children without learning disability is not known. Furthermore, the views and experiences of children with learning disability are almost non-existent in the literature.

A key strength of our study is that it was designed to generate evidence of both the issues that affect all children with long-term conditions and those that are particular to children with learning disability. This evidence is needed to understand the context for making reasonable adjustments for children on the basis of their specific intellectual, emotional, social and physical needs, helping to ensure that resources and interventions that promote equality are better targeted to those who need them, when they need them.

## Aims

- 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.
- To develop guidance for NHS trusts about the implementation of successful and effective measures to promote equal access for children with learning disability and their families.

## Research questions

### *From the perspectives of families and clinical staff*

1. Do children with and children without learning disability and their families have equal access to high-quality hospital care that meets their particular needs?
2. Do children with and children without learning disability, assisted by their families, have equal access to hospital appointments, investigations and treatments?
3. Are children with and children without learning disability and their families equally involved as active partners in their treatment, care and services?
4. Are children with and children without learning disability and their families equally satisfied with their hospital experience?
5. Are safety concerns for children with and children without learning disability the same?
6. What are the examples of effective, replicable good practice for facilitating equal access to high-quality care and services for children with learning disability and their families at the study sites?
7. What indicators from the data and the literature suggest that the findings may be generalisable to other children with long-term conditions in the hospital setting?

## Design

We used a four-phase, transformative, mixed-methods case study design (Creswell JW, Plano Clark VL. *Designing and Conducting Mixed Methods Research*. 2nd edn. London: SAGE Publications Ltd; 2011).

Acknowledged for giving 'a voice to the powerless and voiceless' (Tellis W. Application of a case study methodology. *Qual Rep* 1997;**3**), the case study approach enabled the views of children with LD and their parents to be prioritised and explored 'in depth and within its real-life context' (Yin RK. Enhancing the quality of case studies in health services research. *Health Serv Res* 1999;**34**:1209–24). The production of thick, rich descriptions of the phenomena, using in-depth interviews and creative research methods, means that the complexities of the situation and the factors that can contribute to those complexities emerge. In this study, for every two children with learning disability who were recruited, a child without learning disability was also recruited, thereby allowing the experience of the two groups of patients to be compared.

## Methods

### Phase 1

#### Aim

The aim was to describe the organisational context for health-care delivery to children with learning disability and their families.

#### Setting

Twenty-four hospitals in England (15 specialist children's hospitals and nine non-children's hospitals).

#### Recruitment and consent

A local collaborator for each participating site identified and approached eligible staff to take part in an interview and provided them with an information leaflet. All staff who took part provided written informed consent. Staff eligible to be surveyed were e-mailed a link to an online survey by the local collaborator, with paper copies also available. The return of a completed survey was taken as consent to participate.

## Methods

- Semistructured interviews with senior clinical or managerial staff who had specific responsibility for learning disability, and clinical staff working in a dedicated learning disability role ( $n = 65$ ).
- A content analysis of hospital documents.
- An anonymous online survey of clinical and non-clinical staff who have contact with children ( $n = 2261$ ).

### Phase 2

#### Aim

The aim was to carry out case studies to compare the care and experiences of children with and children without learning disability and their families ( $n = 63$ ).

#### Setting

Four specialist children's hospitals and three non-children's hospitals in England (from phase 1).

#### Recruitment and consent

The principal investigator or research nurse at each site identified eligible children and families. A purposive sampling strategy with a sampling matrix was used to ensure diversity according to the

severity of the child's learning disability and the child's age, reason for admission and length of stay. Four versions of patient information leaflets were available to facilitate inclusion of children of different ages and abilities. Parents provided written informed consent for their and their child's participation. Children provided verbal or written assent, with agreement confirmed just prior to data collection. Where possible, the consent/assent process took place in the family home to enable researchers to build rapport with families, ascertain the child's abilities and interests so that data collection activities could be tailored, and ensure that the study questions were relevant and sensitive.

During the parent interviews, participants were asked to identify hospital staff involved in caring for their child whom we could invite to take part in an interview. These names were passed to the principal investigator or research nurse, who provided these staff members with an information sheet and a consent form and established their willingness to be interviewed. The contact details of those who agreed were passed to the research team.

Community staff were recruited via an e-mail sent by the principal investigator or research nurse, and the e-mail included a synopsis of the study, a link to the online survey and guidance on completion, and study contact details. Submission of the survey was taken as consent to participate.

## Methods

### Children

A multimodal approach was used based on the premise that children are experts about their own lives and should be enabled to share their experience in accordance with their abilities and preferences. Researchers spoke to parents on the telephone in advance of data collection to ascertain how the data collection activities needed to be tailored for their child. Three activities were available to elicit data: Modified Talking Mats™ (Talking Mats Centre, Stirling, UK), a sticker exercise about their interactions with hospital staff and a hospital tour using photography. For children *unable* to participate themselves, parents were invited to participate as a proxy, providing answers from the perspective of their child. Data collection primarily took place at the bedside.

### Parents

Four data collection methods were available for parents to share their views and experiences: (1) a hospital diary, which could be completed at any time of the day or night during the child's admission, offering parents flexibility; (2) photographs of three things that worked well and three things that could be improved about the hospital experience using a camera provided; (3) a safety review form completed just prior to the child's discharge; and (4) a semistructured interview, completed as soon as possible after the child's discharge.

### Staff

Semistructured face-to-face or telephone interviews were held with staff, which lasted 30–60 minutes ( $n = 98$ ). In addition, retrospective mapping of hospital activity and a survey of community professionals ( $n = 429$ ). Child, parent and staff data collection sessions were audio-recorded and transcribed verbatim with participants' permission.

## Phase 3

### Aim

The aim was to compare (1) children's and (2) parents' satisfaction with hospital care.

### Setting

As per phase 2.

### Recruitment and consent

Data collection took place on up to four wards identified by the principal investigator or research nurse. These wards were sampled to ensure that at least one medical and one surgical ward were included, and that there was a throughput of children with and children without learning disability who were aged between 5 and 16 years. Neonatal units and intensive care units were excluded. Some hospitals had fewer than four wards, in which case all eligible wards were included. All children and their parents admitted during the data collection period were eligible to participate. To facilitate ease of distribution and collection of surveys, no exclusion criteria were applied and parents were asked to self-select if their child had a long-term condition, learning disability, neither or both. Participants were advised that returning a completed survey was taken as their consent to participate.

### Methods

A children's ( $n = 803$ ) and a parents' ( $n = 812$ ) survey were distributed to families by the clinical team prior to the child's discharge. An artist was commissioned to develop images for the children's survey to sit alongside each question in an easy-read format, with a corresponding 'thumbs-up' or 'thumbs-down' and 'smiley' or 'sad face' tick box for children to indicate their response. The survey was developed for use with *all* children, irrespective of their age or perceived ability. Children could complete the survey independently or assisted by their parent, or the parent could complete it on their behalf, as proxy, if the child was unable to. The parent survey was available in seven languages other than English.

### Phase 4

#### Aim

The aim was to synthesise and disseminate study findings and develop the content for a training DVD. (digital versatile disc)

#### Setting

As per phase 2.

#### Methods

Consultation occurred with hospital staff at study sites as well as at an open dissemination event, and consultation with parents took place at a specialist children's hospital through study feedback sessions and individual conversations.

### Data analysis

Qualitative and quantitative data were analysed within each phase before being merged and connected using data synthesis; congruence and incongruence were sought between data sets. Each data set was analysed by at least two members of the research team. Barriers to and facilitators of high-quality hospital care were identified for each data set and then brought together, allowing the factors identified by staff, parents and children to be compared. Specific examples of successful and effective measures that promote equal access were also identified. The analytical framework was compared with our initial theoretical framework in order to generate a final empirical framework of factors that affect the promotion of equal access to high-quality hospital care for children with and children without learning disability and their families. Qualitative data were managed and analysed thematically, supported with NVivo (QSR International, Warrington, UK). Quantitative data were analysed using parametric and non-parametric descriptive statistics.

### Results

Nationally, there is considerable uncertainty about and variation among hospitals in terms of the policies, systems and practices that are in place *specifically* for children with learning disability, with

many senior managers not knowing whether or not a specific learning disability policy exists in their organisation. Furthermore, only just over half (53%) of all children's hospitals have a dedicated learning disability nurse post, which differs widely in terms of job role, tenure and remit, and just over half of children's hospitals have a learning disability flagging and alerting system in use, which also varies in terms of their effectiveness to inform staff of a child's learning disability and what that means for them. Moreover, only 2 out of 24 hospitals reported having any formal mechanism for recording learning disability as part of complaints and clinical incidents.

Phase 1 survey data showed significant differences in staff views in relation to children with learning disability having access to high-quality hospital care that meets their particular needs; having access to hospital appointments, investigations and treatments; being involved as active partners in their treatment, care and services; and being safe, indicating perceived inequality comparative to children without learning disability in response to each of our research questions. Areas of practice that showed the greatest difference in hospital staff views were in relation to staff knowledge, skills and training to meet the needs of children with learning disability, including their confidence in communicating effectively with them, managing their pain and safely managing their challenging behaviour; having access to necessary resources and an environment that is safe and appropriately designed to meet the children's needs; and being able to deliver safe care. Staff also perceived that children with learning disability were valued less and treated with less dignity and respect than children without learning disability.

Phase 2 data showed that the experience of individual children, both those with and those without learning disability, and families was overwhelmingly impacted by the individual health-care professional caring for them at any given time, with lack of consistency in the attitudes, practices, skills and knowledge of staff working on the same ward at the same time, and across different wards and hospitals. Furthermore, the suitability of the hospital environment for children with learning disability and the availability of appropriate resources and equipment differed. This variability was found to lead to uncertainty for parents and children, especially those with learning disability, about what to expect in terms of their hospital experience and the 'rules of engagement', leading to an over-reliance on selected staff and creating heightened anxiety when those key people were not present. Although the safety of the child underpinned the role that *all* parents played in hospital, parents of children with learning disability adopted a particularly heightened sense of vigilance compared with parents of children without learning disability.

Similarly, staff often came to rely on parents being present with their child because of, for example, a lack of familiarity with the child, a lack of staffing or a lack of skills and confidence. The key issue, however, was a lack of awareness and knowledge about the non-medical needs of children with learning disability, particularly in advance of an admission, and hence a lack of individualised care that incorporates necessary reasonable adjustments.

## Conclusion

Staff are being let down by an inadequate system, and the negative attitudes and assumptions of the minority of staff, which can have a lasting impact on parents and children, need to be addressed. The findings serve as a useful guide for trusts about how best to meet the Learning Disability Improvement standards that have been set (NHS Improvement. *The Learning Disability Improvement Standards for NHS Trusts*. London: NHS Improvement; 2018. URL: [www.england.nhs.uk/wp-content/uploads/2020/08/v1.17\\_Improvement\\_Standards\\_added\\_note.pdf](http://www.england.nhs.uk/wp-content/uploads/2020/08/v1.17_Improvement_Standards_added_note.pdf); accessed 21 October 2021). What is needed to ensure equality and equity is a joined-up, cohesive approach to the management and governance of learning disability health care at all levels that facilitates the development of an 'institutional memory' of the specific child rather than relying on the 'individual memory' of a particular member of staff.

## Approvals

Full ethics and health research authority approval for this study was obtained before the study commenced (London–Stanmore Research Ethics Committee, reference 16/LO/0645). Local research and development approval was also obtained from each of the 24 participating hospital sites.

## Study registration

The study has been registered on the National Institute for Health and Care Research (NIHR) Clinical Research Network portfolio as 20461 (phase 1) and 31336 (phases 2–4).

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