



## KEY POINT SUMMARY

### OBJECTIVES

This ethnographic study sought to understand the needs of children and young people with learning disabilities (LDs) and their families when they come into a hospital setting; data collection was focused on healthcare professionals.

## Individualizing hospital care for children and young people with learning disabilities: It's the little things that make a difference

Oulton, K., Sell, D., Kerry, S., & Gibson, F. 2015 | *Journal of Pediatric Nursing*  
Volume 30, Issue 1, Pages 78-86

### Key Concepts/Context

This study was conducted in England.

People with learning disabilities (LDs) represent one of the largest groups with a lifelong disability, reaching nearly 60 million people worldwide. In England alone, it is estimated that 1.5 million people live with an LD, 286,000 of them being children and young people ages 0-17. It has been found that those with LD have more hospital admissions and greater hospital stays than those children without.

Following a 2007 report released by Mencap that detailed six adults with LD deaths, recommendations were made available to hospitals in transforming their care delivery to those with LD. It remains unclear whether these care delivery recommendations are suitable for children and young people with LD. There is quite a lack of literature outlining the needs of children and young people with LD and their families. Evidence is also lacking in staff experiences in caring for this patient population; this article seeks to fill this gap.

Of the available literature, communication with staff was cited as the biggest issue that needs addressing. Parents felt an obligation to communicate for their child, thus making parents fearful of leaving their child at the hospital in the care of staff.

### Methods

This ethnographic study involved five data collection methods, including participant observation in a hospital ward over a 12-month period, informal conversations with hospital staff, discussion with children and youth with learning disabilities and their parents, review of hospital ward documentation, and structured interviews with hospital-wide staff. In order to gain access to the ward, researchers spent three months informing staff of the study, and obtained consent from 135 participants.



Following consent, observations were conducted of medical ward rounds, multidisciplinary team meetings, psychosocial meetings, and general ward activity. Outpatient consultations with children and youth were also included.

Purposeful sampling was used to obtain 27 participants for structured interviews. Interviews ranged from 30-70 minutes; staff were asked a series of open-ended questions such as, “Describe your experience for caring for children and young people with learning disabilities and their families,” and to reflect on what has worked well and what has been challenging. Researchers also asked staff to describe the availability and suitability of training prior to caring for these patients. Interviews were recorded and transcribed verbatim.

Ritchie & Spencers Framework approach was used as a data organizational tool following data collection. Using this approach, researchers went through five data management phases: familiarization with interview transcriptions, identifying a thematic framework, indexing data, charting summarized data, and mapping and interpreting data.

Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman, & R. D. Burgess (Eds.), *Analyzing qualitative data* (pp. 173–194). London: Routledge.

## Findings

The final interview sample of 27 hospital staff included 10 nurses and 10 allied health professionals. The majority of participants had worked with children and young people with LD in more than one setting, and included their experience in other settings during the interview.

Six main themes were identified. First, gaining appropriate experience and training is imperative. Study participants emphasized that staff without adequate training may be unaware of what a patient is capable of. Participants also commented on the lack of opportunity to interact with children and young people with LD that pre-registered nurses have. A lack of knowledge about how to interact with the patient population and manage challenging behavior may instill fear in staff, making them more likely to worry about coming to work. Study participants noted the high value of “Makaton” training for their staff.

Identifying the population was difficult for staff, particularly distinguishing between those with LD and those with challenging behavior, communication difficulties, physical impairment, and developmental delay. There was concern in simply including an LD label without special instruction (e.g., autism) in a patient’s record, for fear that not all patients with this particular LD label have the same needs. More detailed verbal and written documentation was identified as a need. Additionally, a common thread throughout all the data was reliance on parents for additional information regarding their children’s LD. However, new nursing staff may lack the



confidence in asking a parent about their child's impairment, leading to inaccurate baseline information for treatment.

Study participants noted that focusing on “little things” made a big impact in care plans, including meal preference, playing, taking medication, interacting with others, etc. Non-medical needs become equally important as medical needs.

Hospitals overall were thought to be challenging environments for children and young people with LD. Distress sets in when routine is disrupted and unfamiliar environments surround. Study participants noted that creating a safe, familiar environment through low stimuli (low noise levels, low light levels, low motion) and decreased wait time was prioritized. “Sensory rooms” proved to be invaluable in the care of children and young people with LD.

Study participants noted their increased need for appropriate resources, such as height-adjustable sinks and sophisticated hoist systems. Costly items such as iPads were not always available in time of need. Also, the issues of appropriate furniture were also raised. Participants felt that young people with LD should have access to adult-sized furniture in child-focused activities (e.g., coloring).

Finally, data suggested that staff relationship with the parents was central to individualized care planning. Participants described the role of parents as monitors and providers of care, supporting staff in creating a safe and familiar environment. One point of concern raised by nurse participants was their overreliance on parents. On the other hand, hospital staff needs to be careful not to assume that parents of children and young people with LD have expertise in carrying out the necessary care in an unfamiliar environment.

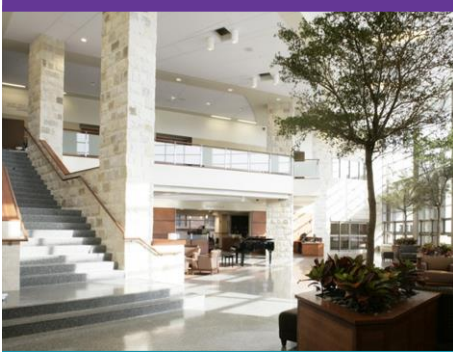
Important to note is the apparent barrier that exists in pediatric tertiary hospital settings and their inability to allow staff to identify and respond to “little things” that strongly impact those with LD.

### Design Implications

Patient care delivery implications outweighed design implications in this article; however, a few design implications were found, including the availability of non-medical equipment. This includes height-adjustable sinks, adult-size furniture, and sophisticated hoist systems.

The study emphasized the importance of an individual care plan for each child or young person with LD. Most important, staff must understand the emotional, physical, and financial cost of overlooking the needs of this patient population.

Lack of exposure to patients with LD and lack of training may lead to poor documenting and overreliance on parent translations, leaving parents concerned over leaving their child even for a short time. Increasing exposure and implementing



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more rigorous training might help to ensure partnership with parents versus overreliance.

Dedicating a role for an LD nurse may help introduce and implement strategies, more appropriately train staff, and ensure patients with LDs have the same experience as those without.

**Limitations**

The author notes that although there was a large participant pool and a wide range of professional backgrounds represented, readers should not assume sample representativeness; highly motivated staff could be overrepresented. In addition, interview participants expressed experiences not just at the study site, but included experience at previous places of employment. Lastly, qualitative interviews may lead to overemphasis of negative practice.

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