



Individualizing Hospital Care for Children and Young People With Learning Disabilities: It's the Little Things That Make the Difference

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This ethnographic study sought parent, patient and staff views about the needs of children and young people with learning disability and their families during hospitalization. Reported here are data from 27 staff. The need for individualized care was identified, based on gaining appropriate experience and training, identifying the population, focussing on the “little things”, creating a safe, familiar environment and accessing and using appropriate resources. Parents played a central role in staff's delivery of individualized care. A lack of staff experience, knowledge and communication about learning disability can mean they rely on parent's input rather than forming a true partnership with them.

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Background

LEARNING DISABILITY (LD) covers a wide spectrum of conditions associated with impairment in learning, including autism and Down syndrome. In the United Kingdom (UK), it is the preferred term of the [Department of Health \(2001\)](#) and the presence of a low intelligence quotient is a defining feature. However, terminology varies internationally, with ‘intellectual disability’ and ‘mental retardation’ also used. According to the *10th International Classification of Diseases (ICD-10)* ([World Health Organisation, 2011](#)) a diagnosis of ‘mental retardation’ is considered ‘definite’ if reduced intellectual functioning results in “diminished ability to adapt to the daily demands

of the normal social environment”, but notably there can be wide variations in the levels of skills developed by individuals. Learning disability does not include children and young people who have specific learning *difficulties* that may impair their educational attainment, e.g. auditory processing problems, but who are within the average range of intelligence. Moreover, those with global developmental delay, who fail to meet their expected developmental milestones in multiple areas of intellectual functioning do not always meet the criteria for learning disability as they grow older ([American Psychiatric Association, 2013](#)).

People with learning disability (LD), estimated at approximately 60 million worldwide, represent one of the largest groups of people with lifelong disabilities ([International Association for the Intellectual Study of Intellectual Disabilities, 2002](#)). It is estimated that there are 1.5 million people with LD in England alone, approximately 286,000 of them are children and young people aged 0–17 years, with

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numbers increasing steadily year on year (Emerson & Hatton, 2008). As well as having intellectual impairment, these children and young people may be physically disabled and have co-occurring impairments such as communication difficulties, sensory impairment, challenging behavior, mental health problems and/or complex long-term health needs, including dependence on technological equipment for their survival (Beresford, 1994; Emerson, Hatton, Felce, & Murphy, 2001; Roberts & Lawton, 2001). They have more hospital admissions and greater lengths of hospital stay than children without disabilities (Mahon & Kidirige, 2004), sometimes attending the same hospital several times in a week (Kennedy, 2010).

In 2007, a UK charity for people with LD (Mencap) produced a report (Mencap, 2007) detailing the case histories of six adults with LD who had died in hospitals from avoidable conditions. Mencap called on the government to take “serious action” and an Independent Inquiry into access to healthcare for people with LD followed. This inquiry identified the invisibility of people with LD within health services, and the lack of priority given to identifying their particular health needs. Patients with LD were found to be treated less favorably than others, resulting in prolonged suffering and inappropriate care (Michael, 2008). Of particular relevance, is the finding that both parents and carers of adults and *children* with LD:

Find their opinions and assessments ignored by health-care professionals...They struggle to be accepted as effective partners in care by those involved in providing general healthcare; their complaints are not heard; they are expected to do too much of the care that should be provided by the health system and are often required to provide care beyond their personal resources.

Following this inquiry and a review of the deaths of 247 people with LD in southwest England, recommendations were made available to support hospitals in transforming the services they deliver to people with LD (Michael, 2008; Improving Health & Lives Learning Disabilities Observatory, 2012). What remains unclear is how far these can and should be applied to children and young people with LD. Their direct relevance to children and young people is not discussed and there is no guidance on the best way to implement them in the paediatric setting. Within the National Service Framework for Children, Young People and Maternity Services (Department of Health, 2004) the distinct service requirements of disabled children are recognized, as is their greater need for personalized, child-centred care. However, the specific needs of children and young people with LD and their families are not addressed. There is a dearth of literature focussing on the issues associated with the hospitalization of children and young people with LD and their families. The few researchers who have asked parents about their own and their child’s experience reveal parental feelings of stress, anxiety and fear, an expectation to provide care while being under-used as a resource by professionals, a lack of trust and confidence in staff

and insufficient information and preparedness (Avis & Reardon, 2008; Brown & Guvenir, 2009; Carter, McArthur, & Cuncliffe, 2002; Oulton & Heyman, 2009; Sharkey et al., 2014). Communication with staff was reported as the biggest issue that needed addressing. Staff interviewed by Sharkey et al. (2014) perceived time pressures and lack of priority given to communicating directly with the child as major barriers. They found that parents could feel a “weight of responsibility” concerning their child’s communication that could make them reluctant to go home and leave their child alone. Furthermore, parents of children and young people with severe LD have revealed that the occurrence of any problems in their child’s care could devastate their trust in the overall system, thereby preventing future uptake of services (Oulton & Heyman, 2009).

Also lacking is evidence of what it is like for hospital staff to care for this group of patients and their families. Research conducted in adult hospitals has shown that staff may not have the knowledge or experience to recognise the additional needs of patients with LD (Tuffrey-Wijne et al., 2014), leading to feelings of fear and anxiety and an over-reliance on patients informal carers (Sowney & Barr, 2006).

Whether these same feelings are experienced by nurses or other staff working in the paediatric setting is not known.

Presented here is one part of a story, that sought to understand the needs of children and young people with LD and their families when they come into hospital: focusing on data from health care professionals. A preliminary model for delivering individualized care to children and young people with LD will be presented, based on staff perceptions of the needs of these patients and the factors underpinning the way care is delivered to them, as well as ethnographic observations of practice. The extensive, rich data collected from children and young people with LD and parents warrant individual attention and therefore will be presented in future papers allowing data to contribute and build incrementally upon the model.

Method

This was an ethnographic study involving (a) participant observation of a hospital ward, (b) informal conversations with ward-based staff (c) repeated ‘discussions’ with children and young people with LD and their parent(s), (d) a review of ward documentation and (e) structured interviews with hospital wide staff. The process of gaining access to the ward environment included a period of 3 months meeting staff, informing them about the study and obtaining consent. A total of 135 ward based staff agreed to be included. Observations were conducted over a period of 12 months and included medical ward rounds, multidisciplinary team meetings, psychosocial meetings and general ward activity. Observations of outpatient consultations involving children and young people who participated in the study were also conducted.

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