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Children with intellectual disabilities and/or complex needs

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The birth of any child leads to new circumstances that require parents and other family members to make significant changes to their lifestyles (Mafuba and Gates, 2015). These changes are more significant and complex when a child has been diagnosed with an intellectual disability and/or complex needs (Barr and Millar, 2003). Carpenter (2005) noted that at diagnosis, parents of children with intellectual disabilities

... are frightened, disturbed, upset, grieving and constantly vulnerable. (p. 181)

According to Gray (2002), parents of children with intellectual disabilities and/or complex needs are more likely to face and experience challenges that are beyond normal societal expectations. When children with intellectual disabilities are born, their parents are likely to experience shock, loss, disappointment, bereavement and self-blame. These reactions are likely to lead to denial, anxiety, parental and family conflicts and conflicts between professionals and agencies. The presence of intellectual disabilities and/or complex needs in children is more likely to result in extended parental needs that are correlated to the degree of their level of intellectual disability, social and cultural background and economic status of the family. The needs of children with intellectual disabilities and/or complex needs will vary over time according to gender, age and level of impairment. In the United Kingdom, the *National Service Framework for Children, Young People and Maternity Services* (DH, 2004) has highlighted the complexity of meeting the needs of children with long-term conditions such as those with intellectual disabilities.

Because of the system of devolution in the United Kingdom, there is no definitive database of children with intellectual disabilities and/or complex needs in the United Kingdom. In England, Emerson et al. (2011) estimated that there were 286,000 children with intellectual disabilities aged 0–17 years. The *Report of the National Review of Services for Disabled Children* (The Scottish Government, 2011) estimated that there were 9232 children with intellectual disabilities in Scotland aged 0–15 years. In Northern Ireland, *Statistics on People with Learning Disabilities in Northern Ireland – Research and Information Service Briefing Paper* (Murphy, 2014) cited McConkey et al. (2003), who estimated that there were 6797 children with intellectual disabilities aged 0–19 years. Statistics for Wales (2015) reported that there were 2842 children with intellectual disabilities aged 0–16 years on the *Local Authority Registers of People with Disabilities*.

In the United Kingdom, services for children with intellectual disabilities are based on a range of medical and social models of disability and these vary between the four countries. Consequently, parents' perceptions of a need for a medical diagnosis of intellectual disability in a child as a gateway to services are often in conflict with models of service provision that are needed to meet the holistic health and social needs of a child. Access to assessment and diagnosis, complexity of health needs, level of intellectual disability, economic status, inequality and inequity of access to services provide a complex context of the experiences of children with intellectual disabilities and their families.

Services for children with intellectual disabilities and/or complex needs need not only be cognizant of their health and social care needs, but those of their families as well as their cultural needs. The *National Framework for Children and Young People's Continuing Care* (DH, 2010) provides an operational framework for the implementation of Standard 8 of the *National Service Framework for Children, Young People and Maternity Services* (DH, 2004). The framework emphasizes the importance of timely assessments and support packages for all children with complex needs (challenging behaviour, communication, mobility, nutrition, continence or elimination, skin and tissue viability, breathing, drug therapies and medicines, psychological and emotional needs or seizures) and their families, including those with intellectual disabilities.

A wide range of themes emerge from the eight articles featured in this special issue. The articles by McCann et al. (2012) and Pelchat et al. (1998) highlight how parents of children with intellectual disabilities experience their caregiving roles. The literature review by McCann et al. (2012) observed that parenting roles for children with disabilities go beyond normal roles. The challenge for parents, and particularly mothers, is to balance parenting and medical care, giving in an environment where models of medical and social care provision are disjointed. The study by Pelchat et al. (1998) explored the variations of parental role expectations and experiences between mothers and fathers. An important observation from this study was that parents' expectations and experiences of having a child with complex needs was rooted in their social conception of the role of 'father' and 'mother'.

Many of the articles focus on parents and the challenges they face: Johnson et al. (2006) explored the experiences of 18 families of children aged 5–15 years with intellectual disabilities and severe challenging behaviours. Being a parent of a child with intellectual disabilities, severe challenging behaviours and/or complex needs is significantly challenging and stressful. This study reports that, in addition, often parents have to cope with the consequences of severe challenging behaviours such as self-blame, social isolation, social and professional conflict and limitations on lifestyle. Whiting (2012) explored and described meaning, need for support and impact of experiences of 33 families of caring for children with 34 children with disabilities, life-limiting/life-threatening illness or technology dependence. The article highlights the importance of building 'trust' between families and the multiplicity of professionals and agencies normally involved when dealing with a child with intellectual disabilities and/or complex needs. This has been advocated for as best practice when caring for children with intellectual disabilities and/or complex health needs for a considerable time (DH, 2004). The study identified early diagnosis as a key factor in parents' experience of having a child with a disability.

The Irish study by Nicholl (2015) investigated the impact of multiple journeys of the mothers and children with physical and intellectual disabilities aged between infancy and 19 years when accessing services. Mothers who participated in this study reported significant challenges necessitating 'pre-emptive caregiving', 'just in case' and dealing with 'no choice' situations. The study also reported that healthcare professionals often lacked understating of the challenges of travelling

with a child with physical disabilities, intellectual disabilities and/or complex needs. As the population of children with intellectual disabilities and/or complex conditions increases, services need to be more coherently structured to minimize the impact of travelling to access services.

Views of parents are explored by Avis and Reardon (2008) through interviews with 16 families of children with intellectual disabilities and complex needs on their perceptions of how their child's needs had been assessed and met while in acute hospital care. The *National Framework for Children and Young People's Continuing Care* (DH, 2010) acknowledges the distinctive additional care and support needs of hospitalized children with disabilities. The researchers observed that healthcare professionals expected parents of children with complex needs to be 'always at the bedside' of their child. The study's conclusions are consistent with that of Whiting (2012) regarding challenges parents of children with complex needs face in building trust with healthcare professionals.

The remaining two articles focus on hospital care and education: Thunberg et al (2015) investigated the hospital care experiences of Swedish parents of children aged 2–12 years requiring augmentative and alternative communication and concluded that effective direct communication between the child and the professionals is essential in meeting their needs. Hewitt-Taylor (2005) surveyed the education and training needs of all staff who come into contact with children with medical- and technology-dependent needs. Findings from the survey show that these children and their families were supported by a wide range of professional and non-professional staff. The study concluded that all such staff require appropriate training.

In conclusion, the findings of the articles in this special issue suggest that policymakers, healthcare providers and healthcare professionals need to take account of the holistic health and social care needs of children with intellectual disabilities and/or complex needs, their families and their cultural needs in order to design appropriate multidisciplinary services.

References

- Avis M and Reardon R (2008) Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study. *Journal of Child Health Care* 12(1): 7–17.
- Barr O and Millar R (2003) Parents of children with intellectual disabilities: their expectations and experience of genetic counseling. *Journal of Applied Research in Intellectual Disabilities* 16(3): 189–204.
- Carpenter B (2005) Early childhood intervention: possibilities and prospects for professionals, families and children. *British Journal of Special Education* 32(4): 176–183.
- Department of Health (DH) (2004) *National Service Framework: Children, Young People and Maternity Services*. London: Department of Health.
- DH (2010) *National Framework for Children and Young People's Continuing Care*. London: Department of Health.
- Emerson E, Hatton C, Robertson J, et al. (2011) People with learning disabilities in England 2011. Available at: https://www.improvinghealthandlives.org.uk/publications/1063/People_with_Learning_Disabilities_in_England_2011.
- Equality Act 2010. Available at: <http://www.legislation.gov.uk/ukpga/2010/15/contents>.
- Gray DE (2002) Everybody just freezes. Everybody is just embarrassed: felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness* 24(6): 734–749.
- Hewitt-Taylor J (2005) Caring for children with complex needs: staff education and training. *Journal of Child Health Care* 9(1): 72–86.

- Johnson RF, O'Reilly M and Vostanis P (2006) Caring for children with learning disabilities who present problem behaviours: a maternal perspective. *Journal of Child Health Care* 10(3): 188–198.
- Mafuba K and Gates B (2015) Learning disability nursing throughout the lifespan. In: Gates B and Mafuba K (eds) *Learning Disability Nursing: Modern Day Practice*. London: Taylor and Francis, pp. 51–81.
- McCann D, Bull R and Winzenberg T (2012) The daily patterns of time use for parents of children with complex needs: a systematic review. *Journal of Child Health Care* 16(1): 26–52.
- McConkey R, Spollen M and Jamison J (2003) *Administrative Prevalence of Learning Disability in Northern Ireland – Report to Department of Health and Social Services and Public Safety*. Belfast: Department of Health and Social Services and Public Safety.
- Murphy E (2014) *Statistics on People with Learning Disabilities in Northern Ireland - Research and Information Service Briefing Paper*. Belfast: Northern Ireland Assembly.
- Nicholl H (2015) 'Going between worlds': travelling with children with complex needs. *Journal of Child Health Care* 19(3): 293–303.
- Pelchat D, Lefebvre H and Perreault M (2003) Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care* 7(4): 231–247.
- Statistics for Wales (2015) *Local Authority Registers of People with Disabilities*, Wales, 31 March 2015. Cardiff: Welsh Government.
- The Scottish Government (2011) *Report of the National Review of Services for Disabled Children*. Edinburgh: The Scottish Government.
- Thunberg G, Buchholz M and Nilsson S (2015) Strategies that assist children with communicative disability during hospital stay: parents' perceptions and ideas. *Journal of Child Health Care*. Epub ahead of print 12 February 2015. DOI: 10.1177/1367493514568298.
- Whiting M (2012) Impact, meaning and need for help and support: the experience of parents caring for children with disabilities, life-limiting/life-threatening illness or technology dependence. *Journal of Child Health Care* 17(1): 92–108.