Parenting children with complex needs

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Home care is now the expected model of care for children with complex needs. For the parents who assume the majority of the care for these children, the role requires extraordinary physical, emotional, social and financial resources (Murphy et al., 2007; Strunk, 2010). This special issue of Journal of Child Health Care recognises the care provided by parents of children with complex needs, through research spanning more than a decade. The research includes parents of children with Down Syndrome, life limiting or threatening conditions, physical, cognitive and learning disabilities, communicative disability, complex health needs, and technology dependence. Six of the studies involve qualitative research with parents (mainly mothers), one study (Hewitt-Taylor 2005) describes a survey of service providers, and the systematic review (McCann et al., 2012) includes 32 studies involving parents caring for a child with complex needs.

The parents describe their experiences of caring for their child with complex needs, the daily struggles and challenges, maintaining family life and relationships, the impact on siblings, the constant need for planning, and the time demands – aspects of caring widely reported in research in this area. A key finding from the systematic review is the often considerable time commitment required by the parents, including time spent supervising or monitoring. The constant monitoring is highlighted by Nicholl (2015), with the mothers in that study literally needing to keep their child within sight at all times. Vigilance is also a key factor in parents of children with complex needs experiencing sleep deprivation and chronic exhaustion (McCann et al., 2015). But the parents also describe the positives associated with caring for a child with complex needs, and how having the child as part of their family enriches all their lives – another theme common to research outside these studies.

The qualitative studies originate from Ireland, England, Canada and Sweden. Despite the differences in health service provision between these countries, there are similarities in the parents’ experiences that raise important questions regarding the support, or lack of support, that parents receive. Three studies (Avis & Reardon, 2008; Johnson et al., 2006; Whiting, 2013) include descriptions of parents having to battle or fight to obtain the supplies or services their child needs. This navigating of the system takes a substantial amount of time (McCann et al., 2012), compounded by the time and energy parents spend attending appointments and coordinating care for their child (Nicholl, 2015; Pelchat et al., 2003).

Parents of children with complex needs cannot sustain the level of care required by their child if they do not receive regular breaks, with research highlighting the physical and mental health costs for parents as a result of the stress associated with the caregiving role (Chen et al., 2015; Dyches et al., 2015; Murphy et al., 2007). But accessing individualised, flexible respite care that meets the needs of the child and their family proves difficult for many parents, particularly when the child has challenging behaviours (Strunk, 2010). And too many parents are telling us that they do not trust respite care providers to provide a suitable standard of care for their child. The parents describe their standards as high and acknowledge that care providers cannot love their child as they do (Ling et al., 2015). But parents should have access to respite care that carries a reassurance that their child is safe and the care provided will be competent and inclusive of the parent’s and child’s needs and wishes. This does not seem too much to ask, particularly considering the high expectations placed on the parents.

Healthcare professionals who support and assist parents and earn their trust are those who respect the parent’s knowledge and expertise, communicate with parent and child, and demonstrate high levels of care and competence. But we learn from the studies published here and elsewhere that this level of care is not always forthcoming and this can have a significant impact on the development of a trusting relationship. Parents in the two studies that focus on experiences when their child is in hospital express the desire that both they and their child be involved in decision making (Thunberg et al., 2015), and want the care they provide in hospital to be negotiated rather than assumed (Avis & Reardon, 2008). The fact that this is not routinely occurring suggests that family centred care, let alone child centred care, remains an ideal rather than a reality for many parents and families. Interestingly, ‘negotiating care’ was identified as a subject to include in education and training for registered nurses providing care for children with complex needs outside the hospital environment by all service providers surveyed by Hewitt-Taylor (2005). Pelchat at al (2003) and Thunberg et al (2015) highlight the
The importance of including the voices of fathers and the children themselves in future research to ensure their stories are heard and their needs met.

For too long, parents of children with complex needs have lacked visibility in our society. The move toward a National Disability Insurance Scheme (NDIS) in Australia provides us with a unique opportunity to take a new look at the way we support children with complex needs and their families. Already there has been a raising of awareness through reports and submissions to taskforces in the lead up to the introduction of the NDIS (Lester & Reid, 2007; National People with Disabilities and Carer Council, 2009) and campaigns such as Every Australian Counts (http://www.everyaustraliancounts.com.au/). It is up to us as researchers, clinicians and service providers to build on the work that is already occurring and develop and deliver best practice models of care that support children with complex needs, their parents and families. If that occurs, the next special issue in Journal of Child Health Care focused on parents of children with complex needs will have much to celebrate.

References


