Planning for the future with Duchenne muscular dystrophy – identifying support structures and approaches that can help

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Background

The 21st century sees the first significant number of men with DMD in the UK surviving well into adulthood due to improvements in medical care, with rates of longevity which could not have been predicted 20 years ago (Eagle, Bourke et al. 2007). Research shows that men with DMD in their late teens and twenties were ‘simply not expected to be alive’ (Abbott and Carpenter 2009, p14) by now. At the time of their diagnosis a future as an adult was not anticipated for them and as a result, there is evidence that their aspirations now for what they can achieve as adults are often low and instances of independent living uncommon (ibid).

While medical care is making future adult lives possible, it is uncertain as to whether support which enables the boys and their families to plan for that future is keeping pace. A UK government group ‘highlighted stark failings in social care and a lack of the support to which people are entitled to enable them to live full and meaningful lives’ (All Party Parliamentary Group for Muscular Dystrophy 2009, p10).

Work on transitions to adulthood for men with DMD shows: there has been little systematic thought about teenagers’ and young men’s futures; medical advances have not been matched by support at home and in the community; and even that support for people with DMD lags behind that of other disabled groups. This paints a disconcerting picture of young men with ‘a strong desire to “get on” with the ordinary business of family life ... often hampered by a lack of support from services’ (Abbott and Carpenter 2009, p146).

Aspirations

Research on disabled children and young people shows that formal support is very important from the early days in setting a context and framework for first how parents and then children think towards the future. Research across a range of lifelong conditions which emerge in childhood has highlighted the crucial significance of how diagnosis is explained to parents affecting how they think about what futures are available to their children (Cunningham, Morgan et al. 1984; Kerr and McIntosh 1998; Williams, Alderson et al. 2002; McLaughlin and Clavering 2007).

Other research has also made clear that providing positive scenarios for the future and enabling children to have high aspirations can have a profound effect on their life choices. If children are exposed to restricted opportunities in everyday life, perceptions of limited horizons become practical limits until they develop, ‘a sense of one’s place which leads one to exclude oneself from the goods, persons, places and so forth from which one is excluded’ (Bourdieu 1984, p417). It can lead to lower aspirations as young people place their own boundaries on the opportunities available to them – known as “pragmatic rationalism” (Hodkinson, Sparkes et al. 1996).

Future Research

At an ENMC workshop on Duchenne Standards of Care in December 2010, the subject of adulthood with DMD was identified as the highest priority subject to be investigated and included in the Standards (Bushby, Finkel et al. 2010; Bushby, Finkel et al. 2010a). If guidance on raising aspirations and planning for the future were contained in the current Standards of Care, this could empower families by providing them with relevant information on planning and promote a sense of control regarding the future (Mitchell and Sloper 2002).

Work needs to be done to build an evidence-base on how best families and professionals can approach adult-futures with Duchenne. Now that there exists an adult population it is important to learn from these young men as they engage with adult life (Wagner, Lechtzin et al. 2007).

Contexts

A range of contexts need to be taken into account:

- the progressive nature of DMD can make future planning uncertain, difficult, or counter-intuitive for families
- this can be compounded if the child has behavioural or learning difficulties which can add levels of complexity in identifying what futures are possible, appropriate and wanted by the young people themselves (Hinton, DeVivo et al. 2004; Hinton, Nereo et al 2006, Hinton, Fee et al. 2007; Poysky 2007; Hendriksen and Vles 2008).
- while parents of disabled children ‘ponder how their grown up kids will manage without them’, and are concerned with their children’s education and economic independence, 70% of them do not plan for their child’s future (Heiman 2002, p167).