



Transition to Adulthood for Young Men with Duchenne Muscular Dystrophy

Research Summary

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Duchenne Muscular Dystrophy (DMD) is an inherited neuromuscular disease which affects boys. During the last few years there have been significant improvements in the ways DMD is managed. As a result, those who are the focus of this study, have reached, or are reaching stages of adulthood that were, at the time of their childhood, largely unexpected. Given increases in life expectancy, young people with DMD should be looking forward to living independently, with appropriate support, as adults. The key objectives of this study was to investigate, from their own perspectives, how the health and well-being of young men living with DMD, and that of their parents, can be maximised, particularly at the transition to adulthood.

Key Findings

- Although around half the families recalled having been involved in some planning for transition for school and from children's to adult services, there was an alarming absence of examples of formal transition planning as required by relevant statutory instruments and policy guidelines. Two thirds of parents had insufficient information about options for what their son did next in his life.
- While many young men had good things to say about their time at school, college and university, there were many examples of systemic failures to meet their needs in relation to physical access, access to a full curriculum and, most commonly, to participation in activities outside of school.
- Families and young people felt that they did not have enough specific information about choices post-school and post-college. Only one young man had had experience of paid work. Others who had looked for work had faced insurmountable obstacles.
- About one third of young men were at home during the day and not doing any kind of education, training or work. Most of them felt that being at home was not stimulating enough and their parents agreed. These young men had very limited social opportunities or friends beyond their immediate family.
- All but three of the forty families interviewed characterised their overall experience of service provision as problematic. Families described having to constantly prove their needs and getting them met was often a protracted and acrimonious process. In a postal survey completed by parents, over 80% reported clinical levels of anxiety and depression. Most had been woken by their son every night of the previous week (average 4.6 nights a week).
- There were very wide variations within and between regions in the nature and level of support available to families in terms of care packages provided. Most parents were still doing a lot of physical care and support.
- The ways in which families talked about living with and being affected by DMD was highly individual. The main theme was that young men said that they preferred not to think about it very much. Parents were not always sure what their sons did, or did not know, about having DMD.
- Both young men and their parents said that they tended to 'live for the day', in large part because the future was so uncertain. There was a strong desire to 'get on' with the ordinary business of family life. The young men with DMD their siblings and parents demonstrated huge resilience in the face of some extraordinary challenges. Relationships within families were often extremely close, mutually supportive and characterised by warmth, humour, and an overwhelming desire to 'lead a good life' despite the obstacles that they faced.

How we did the research

The research comprised:

- A postal survey of parents with a son with DMD aged 15+ living in the South West, the West Midlands and the North East of England.
- Face to face interviews with 40 young men, their parents and siblings (total n=102) about growing older with DMD and the issues they faced at transition.

The data was collected between October 2007 and November 2008.

Additional Information

- A full, 167 page report about the research is available to download here:

http://www.ltn.org.uk/download_files/final%20reports/PRP_Revised_Final_Report_053009.pdf

- An abridged, 49 page version of the research is available to download here:

<http://www.bristol.ac.uk/norahfry/research/completed-projects/becominganadult.pdf>

- A summary of the research written by young men with DMD for other young men is available to download here:

<http://www.bristol.ac.uk/norahfry/research/completed-projects/becomingaman.pdf>

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