

Research Summary:

Understanding Masculinities, Disability, and Transition to Adult Life

What was the purpose of this study?

We wanted to learn more about the experiences of young men growing up with Duchenne Muscular Dystrophy (DMD) as they transitioned into adulthood.

Why is this study important?

Health and social programs help young disabled people get ready for adult life. These programs look at things like independent living, getting a job, going to school, and starting a family. We wanted to find out more about the experiences of male youth to help make these programs and services more responsive to their needs.

What were the study methods?

Eleven young men living with DMD (ages 16 to 27) participated in this study. Six were in high school, one was in university, and the remaining four participants had completed college or university.

Over the course of two weeks, each participant was asked to create a 'photo diary' and an 'audio diary' that revealed their lives and thoughts about transitioning to adulthood. Each then participated in an interview to discuss their diaries and their photos.

Key Findings

What we heard from participants is discussed below under key themes. Participants' names have been changed to protect their privacy.

Living a 'normal life'

Participants discussed their life experiences as both ordinary and extraordinary. Ordinary in that they were living typical lives with the same interests, challenges, and pursuits as other young men. Extraordinary in that they had achieved a 'normal life' in the face of the multiple challenges of living with DMD. These included fatigue, transportation, increasing care needs, and changing mobilities.

"I try to live my life as a normal teen."
(Jean Marc, 17)

"Nothing stops me and gets in the way of my life. I just stay positive and don't worry about the future."
(Mark, 16)

Success in school and work

Achieving success at school or work was highly valued and related to well-being, masculinity and transitioning to adulthood. Participants struggled with future planning after completing post-secondary school. Those looking for work found it difficult for several reasons: they might be unsure of how to go about the process; disability was seen as a barrier by employers; they had difficulties with transportation; and fatigue limited their abilities to work full time.

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“I was an honour student at my school. Also, I won a certificate for the student of the month...I like to work hard.”
(Mark, 16)

Living independently

Living independently was also seen as an important part of transitioning to adulthood, but all participants identified multiple challenges and barriers. They experienced worries about care quality and safety; financial burdens; and would prefer to stay in familiar communities. Some participants preferred to remain at home.

“That’s what you do to move forward in your life...I’m supposed to do that.”
(Michael, 27)

“I have a good support system at home. I’d like to move out just to prove to myself I’ve developed the skills that I need. And just for my own personal ideals.” (Sameer, 21)

Keeping Positive

‘Keeping positive’ was aligned with living a ‘normal life’ and focusing on present accomplishments. Discussions of the progressive nature of DMD were avoided.

“I have to make a decision about having a ventilator when I am older to help me live. I don’t think worrying about it is really going to help. So I’m just thinking positive and being happy, and that is all I should think about.” (Peter, 23)

Recommendations from participants

Key messages:

- The focus on living a ‘normal’ life and a maintaining a positive attitude helped youth to flourish in their daily lives, but may contradict with transition programs oriented to future planning and skills-training.
- Youth with DMD benefit from long term planning in relation to their escalating care needs and major treatment decisions. Timing of information sharing, skills training and decision-making need to be aligned with youths’ desires and readiness to engage in future planning.

For more information, please contact:

Barbara Gibson, Associate Professor
Department of Physical Therapy
University of Toronto
Senior Scientist
Bloorview Research Institute
Holland Bloorview Kids Rehabilitation
Hospital
www.hollandbloorview.ca/research
barbara.gibson@utoronto.ca