

Understanding the transition needs and perspectives of youth and young adults with Duchenne Muscular Dystrophy as they transition to adult health care

TEAM MEMBERS

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RATIONALE

Youth with Duchenne muscular dystrophy and other neuromuscular disorders are living well into adulthood and often need help engaging in meaningful occupations. Our aim was to explore the enablers and barriers to engaging in meaningful occupations from the perspectives of youth, parents, and clinicians.

METHODS

A qualitative design (semi-structured interviews) was used with 11 parents, 8 youth with DMD aged 19-28 (mean 22.3), and 7 clinicians.

Youth with Duchenne Muscular Dystrophy face **barriers** to employment and **support** and **education** is needed from clinicians to help youth achieve their goals



RESULTS

Our results showed that youth with DMD and neuromuscular disorders engaged in meaningful occupations in a variety of ways. Occupational enablers included supports, self-care and coping strategies while occupational barriers involved societal expectations of a normative adulthood, discrimination, lack of supports, medical challenges, and social isolation and depression

DISCUSSION

Clinicians should work to uncover what youth consider important and connect them to appropriate resources so they can engage in meaningful occupations.

CONCLUSIONS

Although there are some supports and resources available to help youth with neuromuscular disorders to engage in meaningful occupations, many youth, parents and clinicians reported that more provisions are needed and barriers removed to help youth as they transition to adulthood.