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

TEAM MEMBERS
Sally Lindsay, Elaine Cagliostrò, Laura McAdam.
Bloorview Research Institute.

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.

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.