

Understanding the participation patterns, strategies, and experiences of adolescents and young adults with progressive neuromuscular conditions

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Michal Waisman-Nitzan
mwaismann@univ.haifa.ac.il

Yonat Ivzori, Dana Anaby

The Gap

- ✓ Transitioning to adulthood for individuals with Duchenne muscular dystrophy is key, especially as their life expectancy has increased.
- ✓ Participation in meaningful occupations across life settings during this phase remains underexplored.

Bendixen et al., 2012; Lindsay et al., 2019; Merkenhof et al., 2025; Travlos et al., 2019

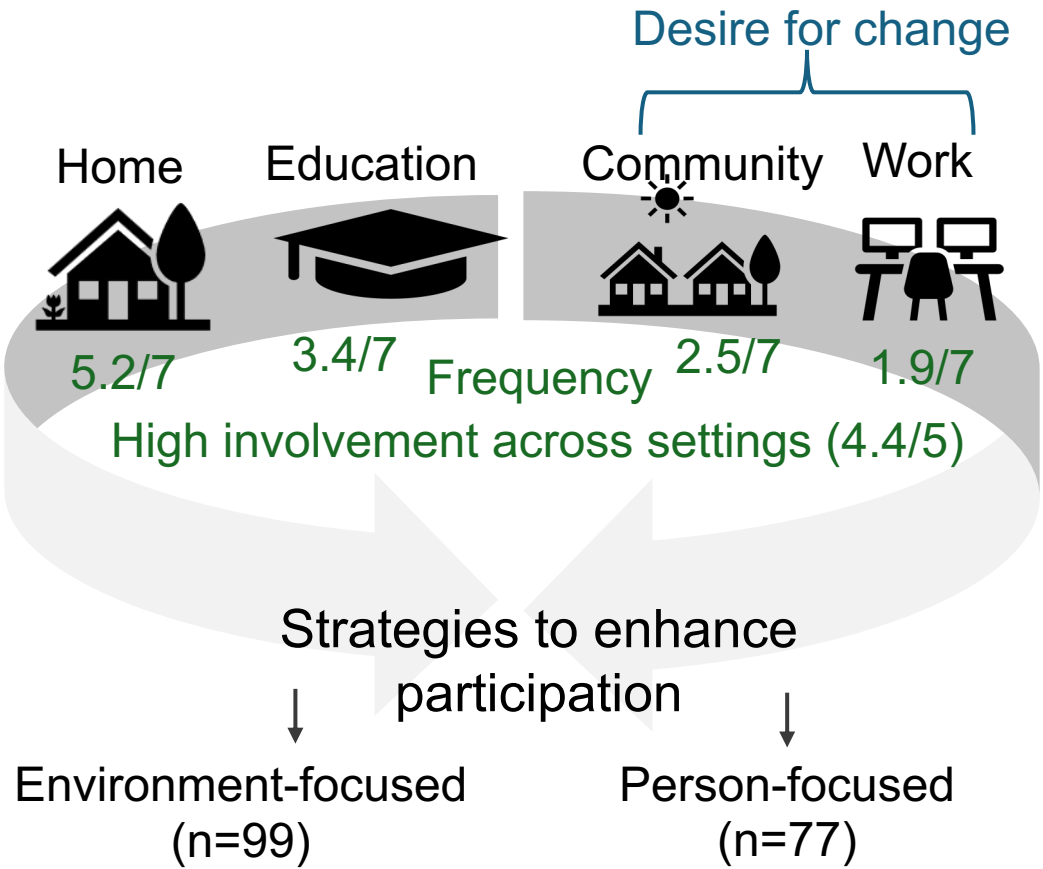
Goals



- ✓ Assess youths' participation across settings
- ✓ Identify strategies to promote participation
- ✓ Explore youth-parent dyadic perceptions of participation

Results

Participation patterns and strategies; 29 participants aged 15-29 years (M=21.5, SD=3.91); Y-PEM (Anaby et al., 2022)



Youth-parent perceptions of participation; 8 Parent-Youth dyads (n=16)



Examples from the participants' lived-experience

My Disability

Functional limitations and their participation consequences

Young-Parent convergence

"...are you crazy? I could never do something like that.... it's like flying to Mars, it's the same level of reality....I'm very realistic; I don't have any fantasies in my head at all" Youth 13

The fact that he is in a wheelchair means that he can't always fit in everything. If they [his friends] go to the beach, if they hike..., he can't join" Parent 13

Take-home message

- Address participation patterns in terms of frequency, involvement, and desire for change
- Acknowledge realistic pragmatic and identity-building aspects of participation among youth with DMD
- Engage youth with DMD and their parents in conversations about participation, recognize the differences in their perspectives, and person- vs environment-based strategies