Project DMD
Transitioning to Adulthood

EXPLORING THE PERSPECTIVES OF YOUNG PEOPLE WITH DUChENNE MUSCULAR DYSTROPHY (DMD), PARENTS/CAREGIVERS AND HEALTH PROFESSIONALS

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Project DMD Overview

Phase 1:
- Semi-structured interviews with young people with DMD (14-25yrs), families and health professionals.

Phase 2:
- Life Profiles
- Transition Planning Tree Tool
- Transition Planning Booklet

Phase 3:
- Implement and evaluate tools and resources with young people with DMD (14-18yrs)

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What is DMD?

- Progressive muscle wasting disease.

- Characterised by muscle weakness & deterioration (Bushby, 2011).

- Increased physical dependence at a time of expected increased independence. (Abbott, Carpenter & Bushby, 2009).

- Loss of typical adult roles due to progressive nature of condition.

- Life expectancy increasing due to advances in medical treatment. (Wagner et al, 2007)

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Plant the seed early on - Create conversations about adulthood

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Planning for an unknown future: What’s around the bend?

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Sharing what’s possible.

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Taking a team approach

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Redefine adulthood: Individualise key milestones.

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Tool Development

- Transition Planning Booklet
- Life Profile Videos
- Transition Planning Tree Tool
Where to now?

- Currently recruiting for Phase 3 of the project.
- Young people with DMD aged 14 to 18 years of age.
- Locations – QLD - Brisbane, Gold Coast, Sunshine Coast, Toowoomba regions.
- Participation - 2 x interviews & 2 x Skype calls + utilization of provided transition to adulthood resources.
- Contact me for further information or to participate.

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Questions?

References

