



Transition to Adulthood with DMD/BMD

ANDREW DONALDSON, DEBRA GUNTRUM, EMMA CIAFALONI, JEFFREY
STATLAND

Background

- ▶ DMD is a relentlessly progressive, chronic disease
- ▶ Median age for loss of ambulation is early teens
- ▶ Progressive muscular weakness can interfere with ADLs
- ▶ 2018 Duchenne Care Guidelines include psychosocial care
- ▶ Little data exists on long-term achievements and outcomes
- ▶ Much of the “standard model of transition” may not apply

Standard Model of Transition

- ▶ Often the transition from Pediatric to Adult Providers
- ▶ College
- ▶ Jobs
- ▶ Marriage
- ▶ Moving out of parents' homes

Study Aims

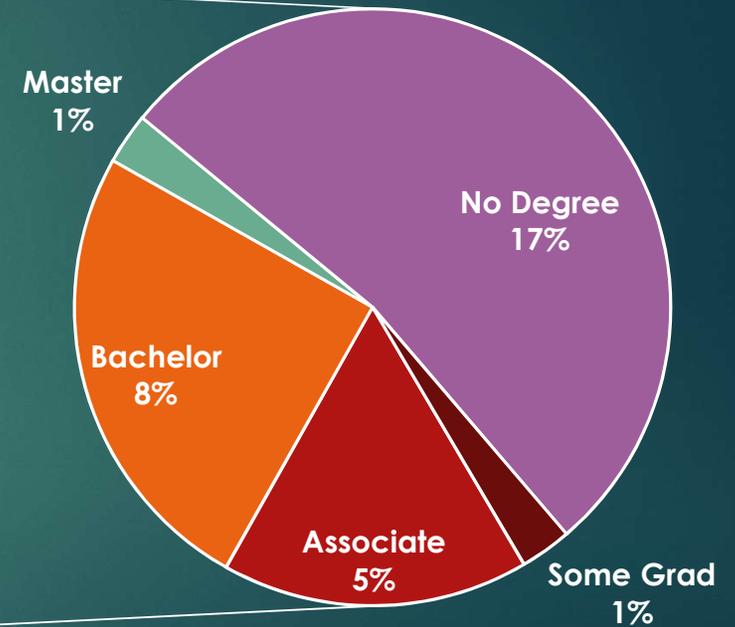
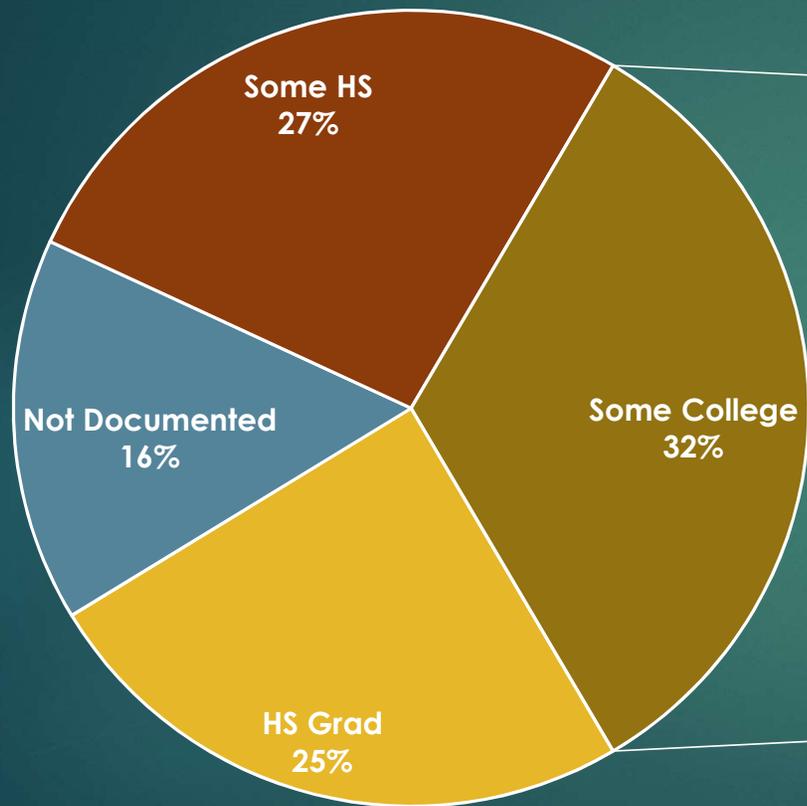
- ▶ Examine the factors impacting the transition to adulthood in DMD/BMD:
 - ▶ Education
 - ▶ Employment
 - ▶ Community Resources
 - ▶ Social Relationships
 - ▶ Medical
 - ▶ Financial

Methods

- ▶ Retrospective chart review at University of Kansas and University of Rochester Medical Centers
- ▶ Inclusion criteria:
 - ▶ Clinical DMD or BMD
 - ▶ Age ≥ 15
 - ▶ > 1 visit with a Neurology provider
 - ▶ Care received from January 2008 – January 2018
- ▶ 109 Charts were identified through MDA Clinic lists, research lists, EMR-generated lists, and backtracking through clinic visits
- ▶ Data was then collected in a common template using Microsoft Excel

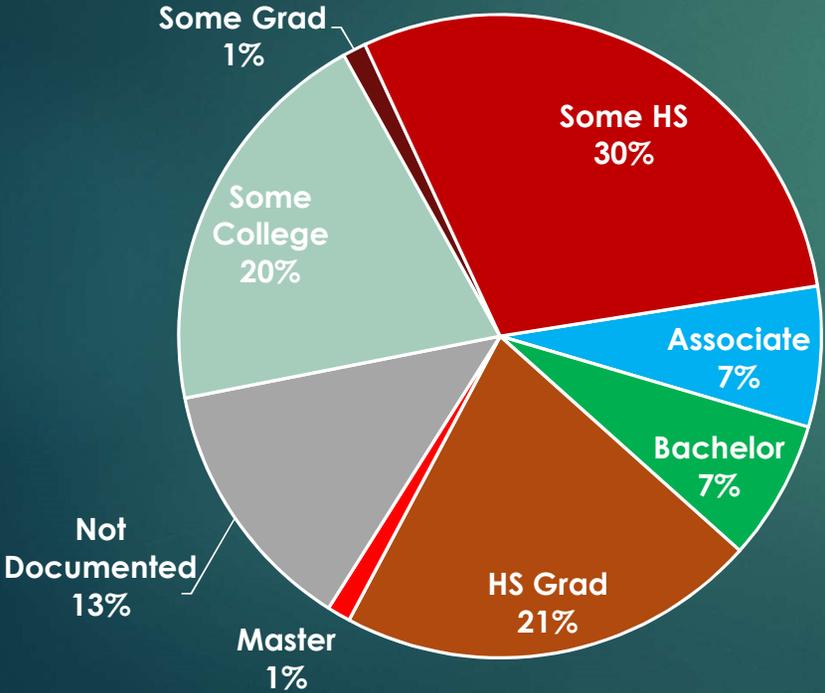
	DMD	BMD	Total
Disease	85 (78%)	24 (22%)	109 (100%)
Median Age	23 (19, 27)	31.5 (23.5, 37)	24 (20, 29)
Environment			
Rural	32 (38%)	9 (37%)	41 (38%)
Urban	52 (61%)	15 (63%)	67 (62%)
Race			
White	78 (92%)	19 (79%)	97 (89%)
Black	4 (5%)	4 (17%)	8 (7%)
Asian	2 (2%)	1 (4%)	3 (3%)
Two or More	1 (1%)	0	1 (1%)
Ethnicity			
Hispanic	2 (2%)	1 (4%)	3 (3%)
Not-Hispanic	83 (98%)	23 (96%)	106 (97%)

Educational Achievements

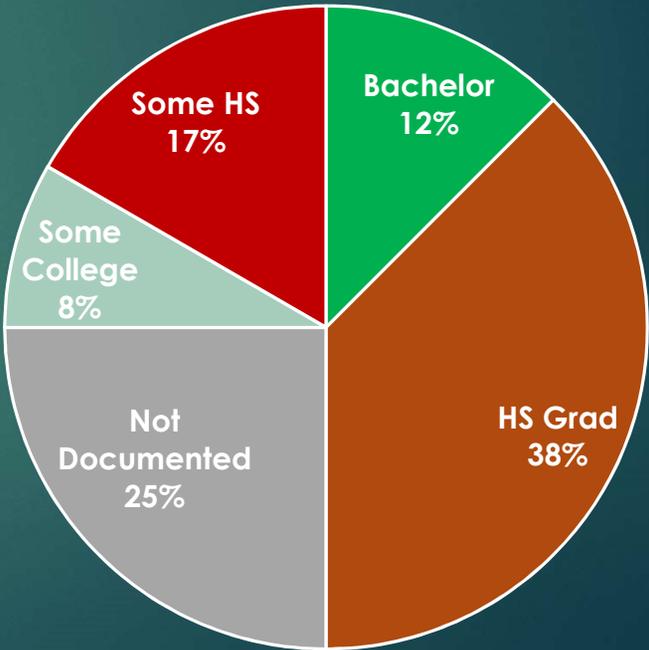


Educational Achievements

DMD

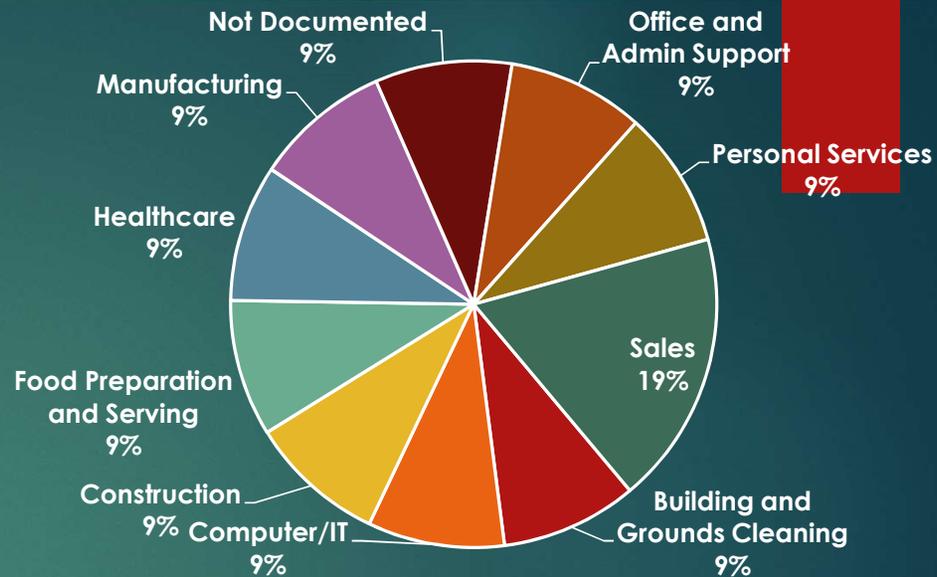


BMD

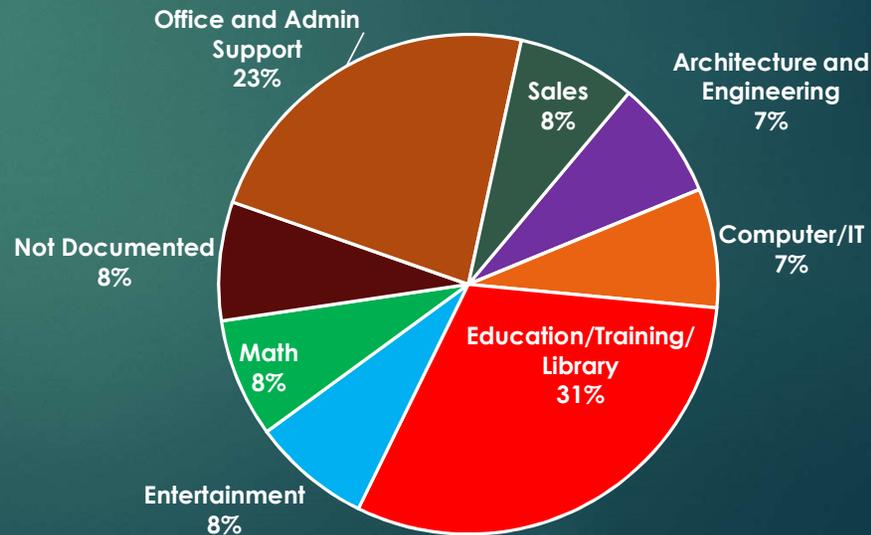


	DMD	BMD	Total
Employed	11 (13%)	11 (46%)	22 (20%)
Volunteer	7 (8%)	0 (0%)	7 (6%)
Neither	65 (76%)	12 (50%)	77 (71%)
Not Documented	3 (4%)	1 (4%)	4 (4%)

BMD



DMD

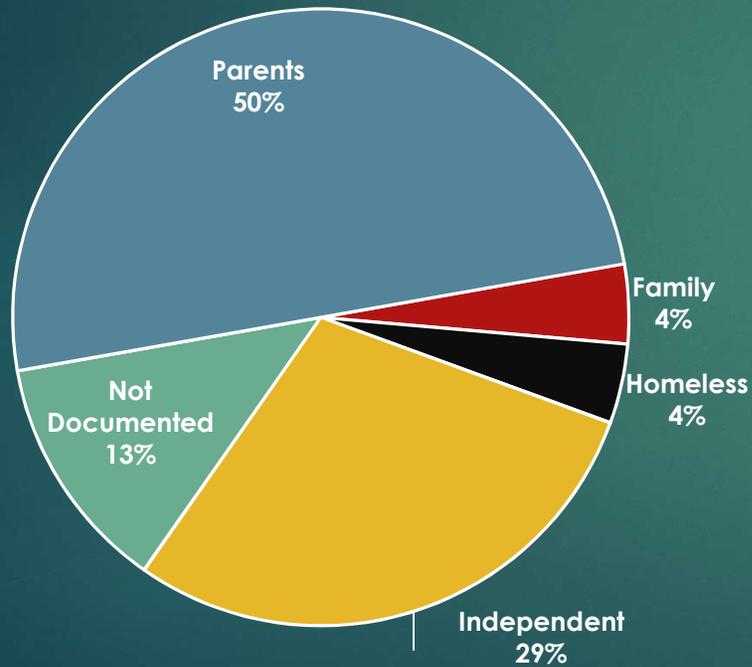


Community Resources

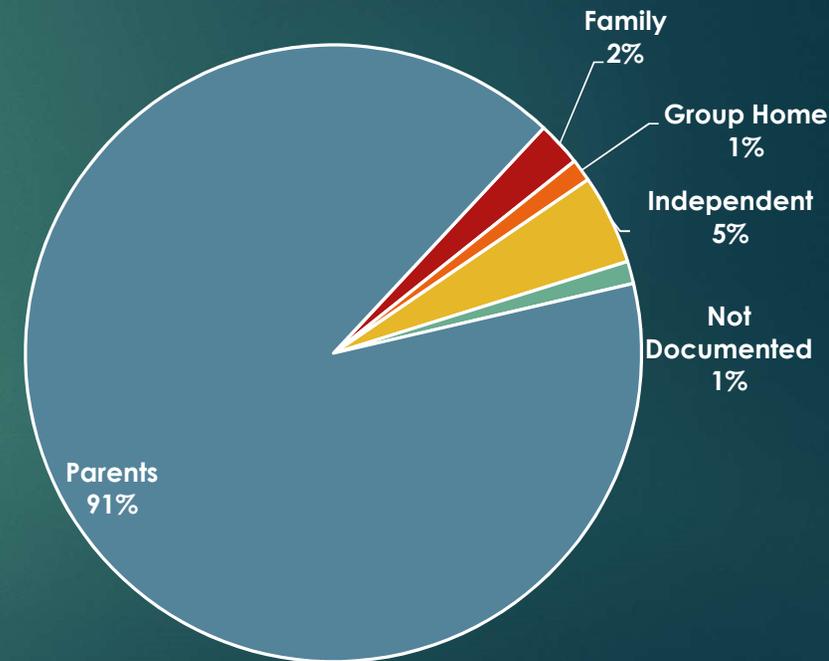
	DMD	BMD	Total
Vocational Rehabilitation			
Yes	3 (4%)	3 (13%)	6 (6%)
No	44 (52%)	6 (25%)	50 (46%)
Not Documented	38 (45%)	15 (63%)	53 (49%)
Personal Care Attendant			
Yes	42 (49%)	4 (17%)	46 (42%)
No	26 (31%)	10 (42%)	36 (33%)
Not Documented	17 (20%)	10 (42%)	27 (25%)

Living Situation

BMD

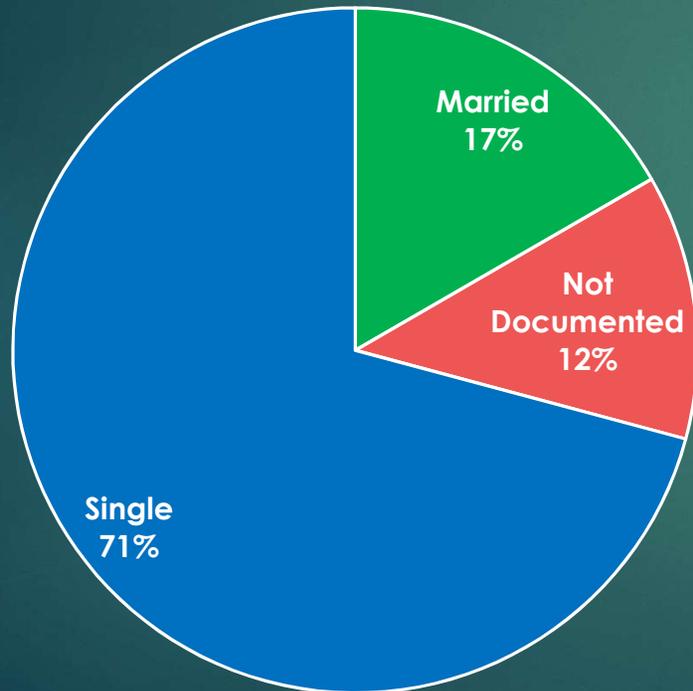


DMD

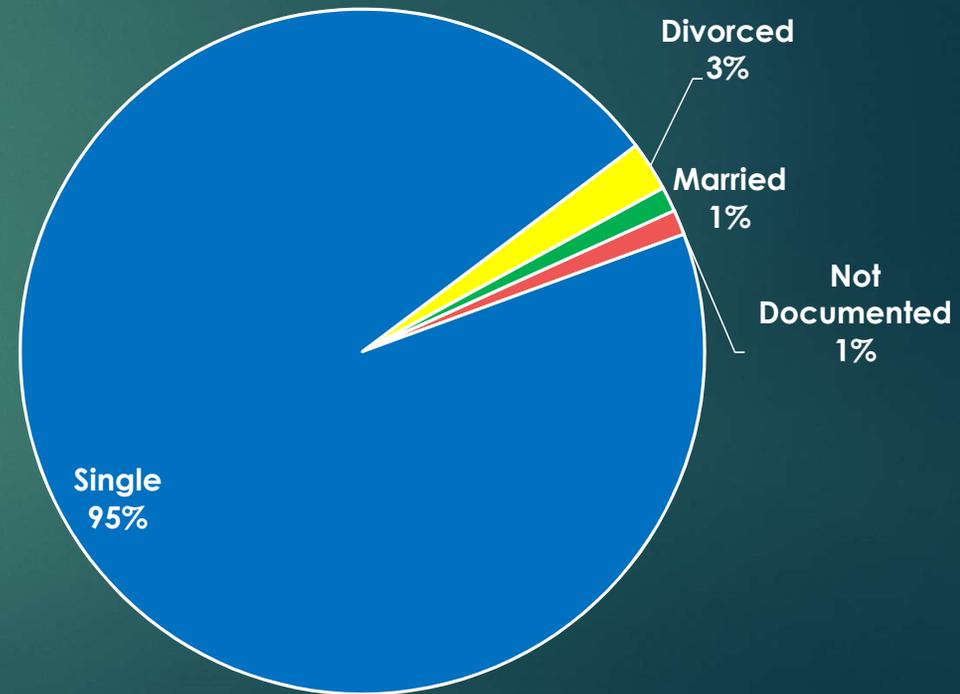


Relationship Status

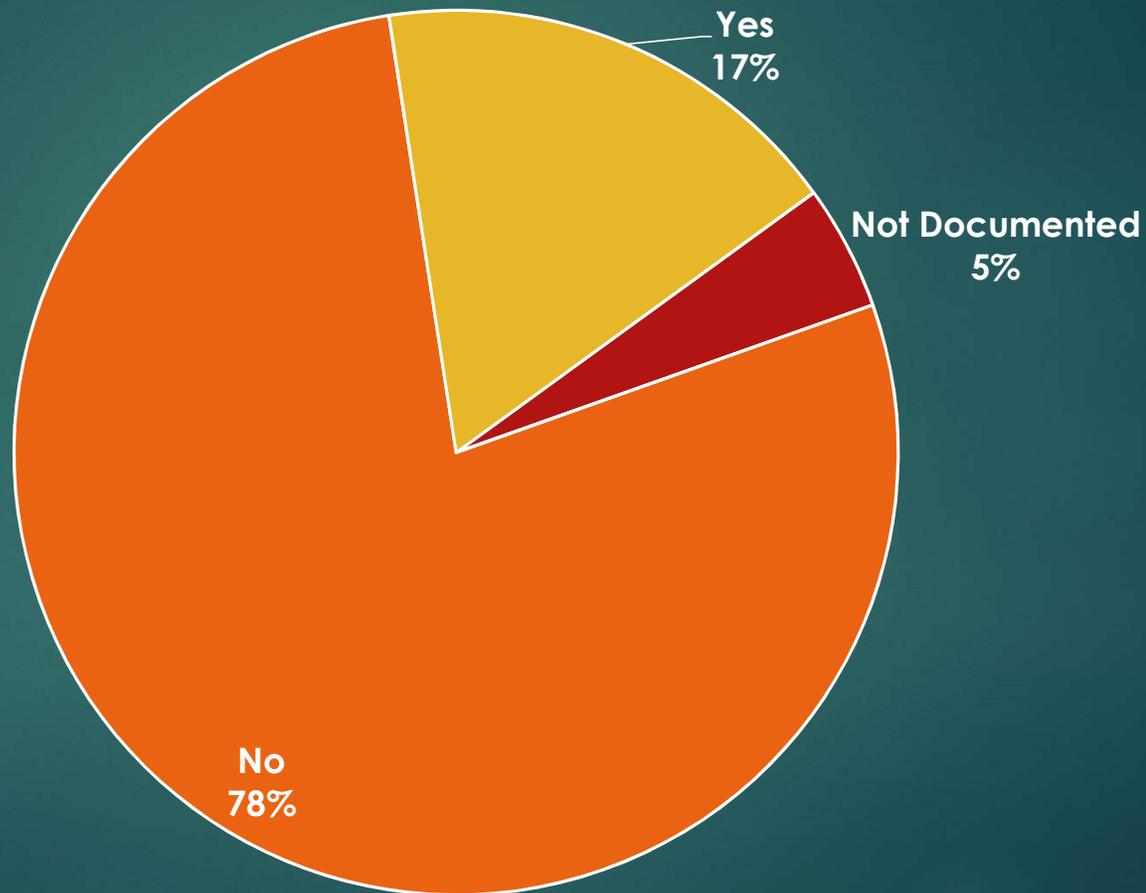
BMD



DMD



End of Life Care Discussion



Conclusions

- ▶ Potential resources are sparingly used
- ▶ Most patients are single and live with their parents
- ▶ 78% of patients have not had an end of life care discussion
- ▶ Data regarding psychosocial development is inconsistently recorded
- ▶ A prospective study is in progress to further elucidate some of this information

Thanks!

- ▶ Deb Guntrum, NP; Drs. Emma Ciafaloni and Jeffrey Statland
- ▶ Dr. Michael Werle, Summer Research Training Program Coordinator
- ▶ The KUMC Neuromuscular Research Team (Richard Barohn, MD, Mazen Dimachkie, MD, Mamatha Pasnoor, MD, Omar Jawdat, MD, Duaa Jabari, MD, Constantine Farmakidis, MD, Laura Herbelin, Kiley Higgs, the DMD coordinators Katherine Roath, and Michaela Walker, and the rest of the NM team!)
- ▶ The KUMC and URMC MDA clinic team of providers
- ▶ The patients and family members!