

Supplemental Table 1. Characteristics of the caregiver, household, affected individual, and source of care provision (n=272).

Characteristics	Frequency	Percent
Caregiver		
Marital Status		
Single, never married	16	5.93
Married or living as married	212	78.52
Widowed	3	1.11
Separated	10	3.7
Divorced	29	10.74
Education		
Grade school	4	1.48
Junior high	5	1.85
High school, no diploma	14	5.19
High school with diploma	50	18.52
Some college, no diploma	63	23.33
Technical college or associate degree	52	19.26
Bachelor's degree	48	17.78
Graduate or professional degree	34	12.59
Household		
Income		
<\$10,000	21	8.43
\$10,000-\$19,999	22	8.84
\$20,000-\$29,999	37	14.86
\$30,000-\$39,999	19	7.63
\$40,000-\$49,999	20	8.03
\$50,000-\$59,999	18	7.23
\$60,000-\$69,999	21	8.43
\$70,000-\$79,999	22	8.84
\$80,000-\$89,999	14	5.62
\$90,000-\$99,999	14	5.62
>\$100,000	41	16.47
Other persons in household with disabilities		
No	226	84.33
Yes	42	15.67
Characteristics Individual with DBMD		
Living Situation		
Both parents, same household	194	71.32
Foster home	0	0
Group home	1	0.37
Independently	6	2.21
One parent	50	18.38
Two parents, different households	12	4.41
Relative	3	1.1
Spouse	2	0.74
Other	15	5.51

Characteristics	Frequency	Percent
Current ambulation		
Walking without help	93	34.32
Walking with help	22	8.12
Manual wheelchair, full-time	8	2.95
Power scooter, full-time	4	1.48
Power wheelchair, full-time	132	48.71
Cannot operate power mobility	7	2.58
Current respiratory function		
No assistance	194	71.32
Bi-pap or c-pap with sleep	37	13.6
Daytime bi-pap or c-pap	5	1.84
Bi-pap or c-pap with sleep and sip-n-puff mouthpiece, breath-stacking during the day	3	1.1
Tracheostomy with part-time ventilation	7	2.57
Trachesotomy with full-time ventilation	10	3.68
Provision of Care		
Caregiver		
No	24	8.92
Yes	242	91.18
Other provide		
No	80	30.08
Yes	180	69.82

Totals may not add up to total sample due to missing values.