

Supplementary Table S2. Frequency distributions and chi-square tests for needs by ambulation status, household income and race/ethnicity.

Need Domains	Overall Needed (n=272)		Ambulation Status				Household Income				Race/Ethnicity			
			Non-Ambulatory (n=151)		Ambulatory (n=115)		<30,000 (n=80)		≥30,000 (n=169)		Minority (n=59)		Non-Minority (n=209)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Home, Community, and Equipment														
1. Identifying appropriate home modifications (knowing what to do) ^a	212	78.5	143	94.7	63	55.8	65	82.3	132	78.6	48	82.8	162	77.9
2. Finding funding for home modifications ^a	192	71.1	137	90.7	50	43.9	62	78.5	116	68.6	45	76.3	147	70.7
3. Finding a builder/contractor for home modifications ^a	163	61.7	120	82.2	39	34.5	48	61.5	103	62.8	38	65.5	125	61.6
4. Finding funding for vehicle modifications ^a	177	65.6	135	89.4	36	31.9	58	73.4	103	61.0	43	74.1	132	63.5
5. Finding accessible public transportation services (buses, rides) ^{a,c}	128	47.8	94	63.1	30	26.6	42	53.9	73	43.7	40	69.0	86	41.8
6. Completing personal care activities (bathing, lifting, toileting) ^{a,b,c}	204	75.8	147	98.0	51	45.1	65	84.4	119	70.4	51	86.4	151	73.3
7. Finding funding for personal care activities (bathing, lifting, toileting) ^{a,b,c}	173	64.3	132	88.0	35	31.0	59	75.6	99	58.9	47	79.7	124	60.2
8. Finding care assistance at home (aides, visiting nurses, attendants, etc.) ^{a,b,c}	155	57.2	124	82.1	26	22.8	52	65.8	88	52.1	44	74.6	109	52.4
9. Identifying appropriate adaptive equipment for walking, standing or mobility ^a	195	72.8	134	90.5	56	49.1	63	80.8	115	68.9	43	74.1	150	72.8
10. Getting funding/insurance to pay for equipment ^a	209	77.7	143	96.0	60	52.6	66	83.5	126	75.5	46	79.3	161	77.8
11. Finding equipment vendors in your community ^a	203	75.2	140	93.3	57	50.0	59	74.7	127	75.6	43	74.1	158	76.0
12. Getting leg braces to fit well & work for your needs	130	48.2	72	48.0	54	47.4	40	50.6	81	48.2	26	44.8	102	49.0
13. Identifying appropriate classroom/job equipment (assistive technology) ^a	175	65.3	123	82.6	47	41.6	52	67.5	110	65.5	39	66.1	134	65.4
Help managing healthcare problems														
14. Joint contractures & muscle weakness ^a	229	85.8	139	93.9	85	74.6	71	91.0	140	83.8	51	87.9	177	85.9
15. Problems with breathing, respiratory illnesses ^{a,b}	128	47.8	95	63.3	29	25.4	44	57.1	72	42.6	33	56.9	95	45.9
16. Heart problems ^a	131	49.1	91	61.5	38	33.3	38	48.7	83	49.7	33	57.9	97	46.9
17. Circulation difficulties & swelling in the feet ^a	92	34.2	75	50.0	16	14.0	25	32.1	59	34.9	26	44.8	65	31.3
18. Bowel & bladder function ^a	140	52.2	102	68.5	33	29.0	47	60.3	81	48.2	33	57.9	107	51.4
19. Diet & nutrition information ^{a,b}	193	71.8	122	81.3	65	57.5	65	82.3	111	66.5	47	81.0	143	69.1
20. Comfort & pain control ^{a,b}	175	65.5	121	81.8	48	42.5	62	79.5	96	57.8	42	75.0	131	63.3
21. Issues relating to sexuality (as age appropriate) ^a	110	41.0	81	54.4	25	21.9	26	33.3	75	44.6	26	45.6	84	40.4
22. Testing for learning disabilities	155	57.6	83	55.7	66	57.9	48	61.5	95	56.6	33	57.9	120	57.7
23. Dental care ^a	231	85.6	146	97.3	79	69.3	72	91.1	141	83.9	53	91.4	176	84.6
Information														
24. Information about inheritance and carrier testing ^c	230	85.2	127	84.1	98	86.7	66	82.5	145	86.3	42	73.7	185	88.5
25. Information about prenatal testing for DBMD	132	49.1	77	51.3	51	45.1	36	45.6	84	50.0	30	51.7	100	48.3
26. Information about the course of the disease ^c	256	95.5	143	96.6	107	93.9	74	93.7	161	96.4	51	91.1	203	97.6
27. Information for talking to family/friends about health concerns related to MD	250	92.6	140	92.7	106	93.0	71	88.8	160	95.2	52	91.2	196	93.8
28. Information on MDA, PPMD or similar organizations	259	96.3	145	96.7	108	95.6	75	94.9	163	97.0	55	94.8	202	97.6
29. Information about financial resources (private, state, federal, etc.) ^{a,c}	255	94.1	146	96.7	103	90.4	75	93.8	160	94.7	52	89.7	201	96.2
30. Access to research updates ^c	259	95.9	144	95.4	110	96.5	75	93.8	164	97.0	53	91.4	204	97.6
31. Access to research participation ^c	255	95.2	144	96.0	106	93.8	73	91.3	161	96.4	52	91.2	201	96.6
32. Information about jobs/future planning for the male with DBMD ^a	195	72.2	122	81.3	68	59.7	54	67.5	124	73.8	42	72.4	151	72.6
33. Information about transitioning to independent adult life ^a	169	64.0	112	76.2	54	48.2	47	60.3	108	65.1	40	70.2	128	62.8
34. Information about how to prepare advance directives: living wills & designating durable power of attorney for healthcare ^a	205	76.2	134	89.3	67	58.8	61	77.2	127	75.2	43	75.4	161	77.0
Psychosocial Issues for Patient with DBMD														
35. Advocating at the school or the workplace	212	79.4	116	77.9	91	81.3	61	78.2	135	80.8	41	71.9	170	82.5
36. Patient discussion/support groups	214	79.6	121	80.7	87	77.0	63	79.8	134	79.8	44	77.2	168	80.8

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37. Counseling to help emotional adjustment (depression, fear, loneliness)	201	75.3	115	77.2	81	72.3	54	69.2	129	77.3	40	71.4	159	76.8
38. Making & maintaining age-appropriate friendships ^a	233	88.3	140	94.6	90	79.7	66	84.6	148	89.7	50	87.7	182	89.2
39. Suggestions for recreational activities alone or with family and friends ^a	235	88.4	138	93.2	91	81.3	69	89.6	147	88.0	50	89.3	183	88.8
Psychosocial Issues for Parent/Caregivers & Family														
40. Balancing work, family & caregiving ^a	245	91.1	145	96.0	94	83.9	70	88.6	155	92.3	53	91.4	190	91.8
41. Finding time and energy for yourself (personal time for the caregiver) ^a	241	89.9	143	95.3	92	82.1	68	86.1	153	91.6	51	87.9	188	91.3
42. Finding time and energy for adult relationships (spouse/significant other) ^a	238	88.8	140	93.3	92	82.1	66	83.5	152	91.0	48	84.2	188	90.8
43. Arranging child care for a child with disability (for parents to work) ^a	164	61.7	103	69.1	56	50.5	50	63.3	103	62.4	39	67.2	123	60.3
44. Finding funding and available respite care so caregivers can be gone ^a	190	70.9	130	86.7	55	49.1	56	70.9	119	71.3	46	79.3	142	68.9
45. Finding or attending parent, spouse or sibling support groups ^b	205	76.8	121	80.1	78	70.9	53	68.0	133	79.6	46	79.3	157	76.6
46. Arranging or getting access to marriage or relationship counseling	124	46.3	75	50.0	45	40.2	35	44.3	78	46.7	27	46.6	96	46.6
47. Counseling to help emotional adjustment (depression, fear, loneliness) ^a	177	66.0	108	71.5	66	58.9	51	64.6	112	66.7	36	62.1	140	67.6
48. Finding appropriate discipline techniques for the child with DBMD	176	65.7	91	60.3	80	71.4	50	63.3	115	68.5	37	63.8	139	67.2

Hawaii excluded. Bolded numbers are significantly different.

^aChi-square for ambulation status statistically significant ($p < .05$). ^bChi-square for household income statistically significant ($p < .05$). ^cChi-square for race/ethnicity statistically significant ($p < .05$).