

Supplementary Table S3. Frequency distributions and chi-square tests for management of needs by ambulation status, household income and race/ethnicity.

Question	Overall Managed* (n=272)		Ambulation Status ^a				Household Income ^b				Race/Ethnicity ^c			
			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) ^{b,c}	159	75.0	110	76.9	44	69.8	42	64.6	107	81.1	29	60.4	128	79.0
2. Finding funding for home modifications ^b	85	44.3	61	44.5	21	42.0	21	33.9	60	51.7	17	37.8	68	46.3
3. Finding a builder/contractor for home modifications ^b	82	50.3	62	51.7	17	43.6	18	37.5	61	59.2	14	36.8	68	54.4
4. Finding funding for vehicle modifications ^{a,b,c}	66	37.3	58	43.0	6	16.7	16	27.6	45	43.7	9	20.9	56	42.4
5. Finding accessible public transportation services (buses, rides, etc.)	71	55.5	51	54.3	19	63.3	21	50.0	42	57.5	24	60.0	45	52.3
6. Completing personal care activities (bathing, lifting, toileting, etc.)	187	91.7	136	92.5	45	88.2	57	87.7	112	94.1	46	90.2	139	92.1
7. Finding funding for personal care activities (bathing, lifting, toileting, etc.)	126	72.8	98	74.2	25	71.4	43	72.9	71	71.7	38	80.9	87	70.2
8. Finding care assistance at home (aides, visiting nurses, attendants, etc.)	103	66.5	83	66.9	17	65.4	33	63.5	60	68.2	32	72.7	71	65.1
9. Identifying appropriate adaptive equipment for walking, standing or mobility ^a	171	87.7	123	91.8	43	76.8	55	87.3	102	88.7	39	90.7	130	86.7
10. Getting funding/insurance to pay for equipment ^a	175	83.7	127	88.8	42	70.0	51	77.3	107	84.9	38	82.6	135	83.9
11. Finding equipment vendors in your community	164	80.8	116	82.9	42	73.7	45	76.3	105	82.7	35	81.4	127	80.4
12. Getting leg braces to fit well & work for your needs ^a	114	87.7	59	81.9	41	94.4	36	90.0	69	85.2	23	88.5	89	87.3
13. Identifying appropriate classroom/job equipment (assistive technology)	136	77.7	90	73.2	41	87.2	40	76.9	86	78.2	30	76.9	105	78.4
Help managing healthcare problems														
14. Joint contractures & muscle weakness ^a	184	80.4	104	74.78	76	89.4	54	76.1	118	84.3	38	74.5	146	82.5
15. Problems with breathing, respiratory illnesses ^a	113	88.3	88	92.6	22	75.9	38	86.4	65	90.3	26	78.8	87	91.6
16. Heart problems ^a	124	94.7	89	97.8	33	86.8	34	89.5	80	96.4	29	87.9	94	96.9
17. Circulation difficulties & swelling in the feet	65	70.7	54	72.0	11	68.8	16	64.0	42	71.2	18	69.2	46	70.8
18. Bowel & bladder function	116	82.9	87	85.3	26	78.8	36	76.6	69	85.2	25	75.8	91	85.1
19. Diet & nutrition information	165	85.5	103	84.4	57	87.7	56	86.2	93	83.8	38	80.9	124	86.7
20. Comfort & pain control	140	80.0	96	79.3	39	81.3	45	72.6	80	83.3	30	71.4	108	82.4
21. Issues relating to sexuality (as age appropriate)	72	65.5	52	64.2	17	68.0	17	65.4	48	64.0	14	53.9	58	69.1
22. Testing for learning disabilities ^c	140	90.3	73	88.0	62	93.9	43	89.6	87	91.6	26	78.8	112	93.3
23. Dental care	201	87.0	123	84.3	72	91.1	59	81.9	126	89.4	44	83.0	156	88.6
Information														
24. Information about inheritance and carrier testing	184	80.0	105	82.7	76	77.6	49	74.2	121	83.5	31	73.8	151	81.6
25. Information about prenatal testing for DBMD	89	67.4	54	70.1	34	66.7	26	72.2	59	70.2	23	76.7	65	65.0
26. Information about the course of the disease	228	89.1	128	89.5	94	87.9	64	86.5	147	91.3	46	90.2	180	88.7
27. Information for talking to family/friends about health concerns related to muscular dystrophy	200	80.0	109	77.9	88	83.0	53	74.7	133	83.1	39	75.0	159	81.1
28. Information on MDA, PPMD or similar organizations ^a	233	90.0	126	86.9	102	94.4	65	86.7	150	92.0	47	85.5	184	91.1
29. Information about financial resources (private, state, federal, etc.)	120	47.1	71	48.6	46	44.7	34	45.3	73	45.6	23	44.2	95	47.3
30. Access to research updates ^c	206	79.5	118	81.9	84	76.4	60	80.0	129	78.7	35	66.0	170	83.3
31. Access to research participation	155	60.8	85	59.0	67	63.2	43	58.9	99	61.5	28	53.9	127	63.2
32. Information about jobs/future planning for the male with DBMD	58	29.7	40	32.8	16	23.5	16	29.6	38	30.7	14	33.3	43	28.5
33. Information about transitioning to independent adult life	55	32.5	39	34.8	14	25.9	16	34.0	33	30.6	13	32.5	41	32.0
34. Information about how to prepare advance directives: living wills & designating durable power of attorney for healthcare	93	45.4	65	48.5	26	38.8	22	36.1	63	49.6	17	39.5	75	46.6
Psychosocial Issues for Patient with DBMD														

Supplementary Table S3. Frequency distributions and chi-square tests for management of needs by ambulation status, household income and race/ethnicity.

35. Advocating at the school or the workplace	167	78.8	93	80.2	69	75.8	46	75.4	108	80.0	32	78.1	134	78.8
36. Patient discussion/support groups ^b	111	51.9	60	49.6	47	54.0	25	39.7	77	57.5	19	43.2	90	53.6
37. Counseling to help emotional adjustment (depression, fear, loneliness, etc.)	99	49.3	56	48.7	40	49.4	21	38.9	70	54.3	17	42.5	82	51.6
38. Making & maintaining age-appropriate friendships ^a	159	68.2	87	62.1	69	76.7	46	69.7	102	68.9	36	72.0	122	67.0
39. Suggestions for recreational activities alone or with family and friends	159	67.7	87	63.0	66	72.5	48	69.6	99	67.4	35	70.0	122	66.7
Psychosocial Issues for Parent/Caregivers & Family														
40. Balancing work, family & caregiving	179	73.1	102	70.3	73	77.7	49	70.0	114	73.6	40	75.5	137	72.1
41. Finding time and energy for yourself (personal time for the caregiver) ^{a,b}	148	61.4	78	54.6	67	72.8	34	50.0	100	65.4	33	64.7	114	60.6
42. Finding time and energy for adult relationships (spouse or significant others) ^{a,b}	144	60.5	73	52.1	67	72.8	30	45.5	99	65.1	30	62.5	113	60.1
43. Arranging child care for a child with disability (for parents to work) ^a	104	63.4	58	56.3	44	78.6	29	58.0	67	65.1	26	66.7	77	62.6
44. Finding funding and available respite care so caregivers can be gone	99	52.1	64	49.2	32	58.2	28	50.0	66	55.5	24	52.2	75	52.8
45. Finding or attending parent, spouse or sibling support groups ^b	96	46.8	53	43.8	38	48.7	17	32.1	68	51.1	21	45.7	74	47.1
46. Arranging or getting access to marriage or relationship counseling ^b	51	41.1	28	37.3	21	46.7	8	22.9	39	50.0	10	37.0	40	41.7
47. Counseling to help emotional adjustment (depression, fear, loneliness, etc.)	71	40.1	43	39.8	28	42.4	18	35.3	47	42.0	14	38.9	57	40.7
48. Finding appropriate discipline techniques for the child with DBMD	103	58.5	57	62.6	45	56.3	26	52.0	70	60.9	18	48.7	85	61.2

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 ($p < .05$).

*Counts for managed items varies depending on reported need by caregiver.