MDCHILD
Muscular Dystrophy Child Health Index of Life with Disabilities

Instructions

1. This questionnaire is about your health, comfort, about caring for your needs, and having a good life.
2. Each section has different choices. Please read the instructions for each section carefully.
3. Please answer all questions by circling the number that fits best. You may write down any comments/clarifications in the space provided below each question.

For example:

Consider how you **usually** perform each of the following activities.

1. Rate how **difficult** each of these activities were in the past 4 weeks for you, **and**
2. Choose the **level of help** you required to perform these activities.

During the past 4 weeks, how difficult was:	*Not Possible (Almost Impossible)*	*Very Difficult*	*Difficult*	*Slightly Difficult*	*Easy*	*Very Easy*	*No problem at all*	**Level of Help: Total Help**	**Some Help**	**A Little Help / Supervised**	**No Help / Independent**
1. picking up an object from the floor?	**0**	**1**	**2**	**3**	**4**	**5**	6	0	**1**	**2**	**3**

In the above example, Joe rated the task of picking up an object off the floor as *no problem at all*, and he reported that he required *total help*. This is because although Joe is unable to pick up an object off the floor by himself, it is not a problem for him because he has someone to help him. On the other hand, if he did not always have someone to help him, he might have rated the task as *not possible* and reported that he required *total help* for that task.

4. At the end of each section there is space for you to add any items that you think are missing from the questionnaire, which you believe are important to your comfort and having a good life.

Study ID: _____

Date: _____

SECTION 1: ACTIVITIES OF DAILY LIVING & INDEPENDENCE

Consider how you **usually** perform each of the following activities.

1. Rate how **difficult** each of these activities were in the past 4 weeks for you, **and**
2. Choose the **level of help** you required to perform these activities.

During the past 4 weeks, how difficult was:	***Not Possible (Almost Impossible)***	***Very Difficult***	***Difficult***	***Slightly Difficult***	***Easy***	***Very Easy***	***No problem at all***	**Level of Help: Total Help**	**Some Help**	**A Little Help / Supervised**	**No Help / Independent**
1. eating/drinking?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
2. brushing and flossing teeth?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
3. bathing/washing?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
4. toileting activities (getting on and off toilet)?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
5. cleaning after going to the toilet?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
6. putting on/taking off upper body clothing? (shirt, jacket, etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
7. putting on/taking off lower body clothing? (pants, sweats, etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
8. putting on/wearing footwear? (socks, shoes, sandals, etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
9. hair care? (washing, drying, brushing, etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
10. picking up an object off the floor?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
11. using a computer, tablet, or smartphone?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
1A. other activity? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
1B. other activity? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**

SECTION 2: POSITIONING, TRANSFERRING & MOBILITY

Consider how you **usually** perform each of the following activities.

1. Rate how **difficult** each of these activities were in the past 4 weeks for you, **and**
2. Choose the **level of help** you required to perform these activities.

During the past 4 weeks, how difficult was:	***Not Possible (Almost Impossible)***	***Very Difficult***	***Difficult***	***Slightly Difficult***	***Easy***	***Very Easy***	***No problem at all***	**Level of Help: Total Help**	**Some Help**	**A Little Help / Supervised**	**No Help / Independent**
12. getting in and out of bed?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
13. transferring into/out of a chair or wheelchair?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
14. sitting in a chair or wheelchair?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
15. standing at a sink/counter?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
16. moving about in the home? (in whatever way possible)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
17. moving about outdoors? (in whatever way possible)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
18. getting in and out of a car, van, or bus?	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
19. visiting public places? (park, restaurants, sports arena etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
2A. other activity? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
2B. other activity? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**

SECTION 3: COMFORT & ENDURANCE

During the past 4 weeks, how often did you experience pain or discomfort	*Every day*	*Very Often*	*Fairly Often*	*A few times*	*Once or twice*	*None of the time*	How Much: A Lot	Some	A Little	None
20. in the feet or ankles?	0	1	2	3	4	5	0	1	2	3
21. in the legs? (lower legs, knees, thighs)	0	1	2	3	4	5	0	1	2	3
22. in the hips?	0	1	2	3	4	5	0	1	2	3
23. in the back?	0	1	2	3	4	5	0	1	2	3
24. in the arms?	0	1	2	3	4	5	0	1	2	3
25. while seated?	0	1	2	3	4	5	0	1	2	3
3A. other pain or discomfort? Specify: _____	0	1	2	3	4	5	0	1	2	3
3B. other pain or discomfort? Specify: _____	0	1	2	3	4	5	0	1	2	3

During the past 4 weeks, how often did you										
26. feel tired easily?	0	1	2	3	4	5	0	1	2	3
27. feel tired during school or work?	0	1	2	3	4	5	0	1	2	3
28. feel tired during activities you enjoy?	0	1	2	3	4	5	0	1	2	3
29. have difficulty sleeping?	0	1	2	3	4	5	0	1	2	3
3C. feel tired during other activities? Specify: _____	0	1	2	3	4	5	0	1	2	3
3D. feel tired during other activities? Specify: _____	0	1	2	3	4	5	0	1	2	3

SECTION 4: EMOTIONS & BEHAVIOUR

During the <u>past 4 weeks</u>, how often were you	*Every day*	*Very Often*	*Fairly Often*	*A few times*	*Once or twice*	*None of the time*	How Much: A Lot	Some	A Little	None
30. frustrated, upset, or angry?	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**
31. unhappy or sad?	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**
32. worried or anxious?	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**
33. unsure of yourself?	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**
34. unable to focus or pay attention?	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**
4A. bothered by other feelings or behaviours? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**
4B. bothered by other feelings or behaviours? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**

SECTION 5: SOCIAL INTERACTION & SCHOOL

Consider how you **usually** perform each of the following activities.

Rate how **difficult** each of these activities were in the past 4 weeks for you.

During the past 4 weeks, how much difficulty did you have	***Not Possible (Almost Impossible)***	***Very Difficult***	***Slightly Difficult***	***Difficult***	***Easy***	***Very Easy***	***No problem at all***
35. playing or spending time on your own? (video/computer games, books, art, etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**
36. getting along with family?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
37. getting along with others?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
38. making and keeping friends?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
39. having a girlfriend or boyfriend?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
40. participating in hobbies with others? (games, movies, video/computer games, etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**
41. participating in physical activities you enjoy? (swimming, adapted sports, camp, etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**
42. keeping up with schoolwork?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
43. communicating with others?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
5A. other social activity? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**6**
5B. other social activity? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**6**

SECTION 6: HEALTH

In the <u>past 4 weeks</u>,	*Stayed in hospital overnight*	*5 or more visits*	*3 to 5 visits*	*Two visits*	*One visit*	*No visits*
44. How many times have you had to visit the doctor or the hospital?	**0**	**1**	**2**	**3**	**4**	**5**

In the <u>past 4 weeks</u>,	*Very Poor*	*Poor*	*Fair*	*Good*	*Very Good*	*Excellent*
45. How would you rate your overall health?	**0**	**1**	**2**	**3**	**4**	**5**

In the <u>past 4 weeks</u>,	*Five or more*	*Four*	*Three*	*Two*	*One*	*None*
46. How many different medicines and vitamins do you take each day?	**0**	**1**	**2**	**3**	**4**	**5**

SECTION 7: YOUR OVERALL QUALITY OF LIFE

In the <u>past 4 weeks</u>,	*Very Poor*	*Poor*	*Fair*	*Good*	*Very Good*	*Excellent*
47. How good is your life?	**0**	**1**	**2**	**3**	**4**	**5**

SECTION 8: IMPORTANCE OF ITEMS TO YOUR QUALITY OF LIFE

Thinking about how you are doing now for each of the items, how much does the item affect your life?	None	A Little	Some	Quite a Bit	A Lot
1. Eating / drinking	0	1	2	3	4
2. Brushing and flossing teeth	0	1	2	3	4
3. Bathing / washing	0	1	2	3	4
4. Toileting activities (getting on and off toilet)	0	1	2	3	4
5. Cleaning after going to the toilet	0	1	2	3	4
6. Putting on / taking off upper clothing	0	1	2	3	4
7. Putting on / taking off lower clothing	0	1	2	3	4
8. Putting on / wearing footwear	0	1	2	3	4
9. Hair care	0	1	2	3	4
10. Picking up an object off the floor	0	1	2	3	4
11. Using a computer, tablet, or smartphone	0	1	2	3	4
12. Getting in and out of bed	0	1	2	3	4
13. Transferring into / out of a chair or wheelchair	0	1	2	3	4
14. Sitting in a chair or wheelchair	0	1	2	3	4
15. Standing at a sink / counter	0	1	2	3	4
16. Moving about in the home	0	1	2	3	4
17. Moving about outdoors	0	1	2	3	4
18. Getting in / out of a car, van, or bus	0	1	2	3	4
19. Visiting public places	0	1	2	3	4
20. Pain or discomfort in the feet or ankles	0	1	2	3	4
21. Pain or discomfort in the legs	0	1	2	3	4
22. Pain or discomfort in the hips	0	1	2	3	4
23. Pain or discomfort in the back	0	1	2	3	4
24. Pain or discomfort in the arms	0	1	2	3	4
25. Pain or discomfort while seated	0	1	2	3	4
26. Feel tired easily	0	1	2	3	4
27. Feel tired during school or work	0	1	2	3	4
28. Feel tired during activities you enjoy	0	1	2	3	4
29. Have difficulty sleeping	0	1	2	3	4
30. Being frustrated, upset, or angry	0	1	2	3	4
31. Being unhappy or sad	0	1	2	3	4
32. Being worried or anxious	0	1	2	3	4
33. Being unsure of yourself	0	1	2	3	4
34. Being unable to focus or pay attention	0	1	2	3	4
35. Playing or spending time on your own	0	1	2	3	4
36. Getting along with family	0	1	2	3	4
37. Getting along with others	0	1	2	3	4
38. Making and keeping friends	0	1	2	3	4
39. Having a girlfriend or boyfriend	0	1	2	3	4
40. Participating in hobbies with others	0	1	2	3	4
41. Participating in physical activities you enjoy	0	1	2	3	4

	None	A Little	Some	Quite a Bit	A Lot
42. Keeping up with schoolwork	**0**	**1**	**2**	**3**	**4**
43. Communicating with others	**0**	**1**	**2**	**3**	**4**
44. Number of visits to the doctor and hospital	**0**	**1**	**2**	**3**	**4**
45. Overall health	**0**	**1**	**2**	**3**	**4**
46. Number of medicines and vitamins	**0**	**1**	**2**	**3**	**4**

SECTION 9: FACTS ABOUT YOU

1. Are you:	☐ **Male** ☐ **Female**
2. What is your date of birth?	_____ / _____ **Month Year**
3. What is the highest school grade you have completed? (check only one grade)	**Preschool** ___ **Kindergarten** ___ **1st Grade** ___ **2nd Grade** ___ **3rd Grade** ___ **4th Grade** ___ **5th Grade** ___ **6th Grade** ___ **7th Grade** ___ **8th Grade** ___ **9th Grade** ___ **10th Grade** ___ **11th Grade** ___ **12th Grade** ___ **Ungraded** ___ **If ungraded, how many years attended?** _____

How long has it taken you to complete this questionnaire only (in units of time): _____

THANK YOU FOR YOUR PARTICIPATION!