MDCHILD
Muscular Dystrophy Child Health Index of Life with Disabilities

MDCHILD PARENT

Instructions

1. This questionnaire is about your child's health, comfort and well-being, and about caring for his/her needs.
2. Each section has different options. 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 each of the following activities is **usually** performed by/for your child.

1. Rate how **difficult** each of these activities were in the past 4 weeks for your child, **and**
2. Choose the **level of assistance** that was required to help your child 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 Assistance: Total Assistance**	**Moderate Assistance**	**Minimal Assistance / Supervised**	**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 child's health, comfort and well-being.

Study ID: _____

Relationship to Child: _____

Date: _____

SECTION 1: ACTIVITIES OF DAILY LIVING & INDEPENDENCE

Consider how each of the following activities is **usually** performed by/for your child.

1. Rate how **difficult** each of these activities were in the past 4 weeks for your child, **and**
2. Choose the **level of assistance** that was required to help your child 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 Assistance: Total Assistance**	**Moderate Assistance**	**Minimal Assistance / Supervised**	**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**

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SECTION 2: POSITIONING, TRANSFERRING & MOBILITY

Consider how each of the following activities is **usually** performed by/for your child.

1. Rate how **difficult** each of these activities were in the past 4 weeks for your child, **and**
2. Choose the **level of assistance** that was required to help your child 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 Assistance: Total Assistance**	**Moderate Assistance**	**Minimal Assistance / Supervised**	**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 vehicle? (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**

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SECTION 3: COMFORT & ENDURANCE

During the <u>past 4 weeks</u>, how often did your child experience pain or discomfort	*Every day*	*Very Often*	*Fairly Often*	*A few times*	*Once or twice*	*None of the time*	Intensity: Severe	Moderate	Mild	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 <u>past 4 weeks</u>, how often did your child										
26. feel tired or fatigued 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 recreational activities?	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

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SECTION 4: EMOTIONS & BEHAVIOUR

During the <u>past 4 weeks</u>, how often was your child	*Every day*	*Very Often*	*Fairly Often*	*A few times*	*Once or twice*	*None of the time*	Intensity: Severe	Moderate	Mild	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. lacking self-confidence?	**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. experiencing other emotions or behaviours of concern? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**
4B. experiencing other emotions or behaviours of concern? Specify: _____	**0**	**1**	**2**	**3**	**4**	**5**	**0**	**1**	**2**	**3**

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SECTION 5: SOCIAL INTERACTION & SCHOOL

Consider how each of the following activities is **usually** performed by/for your child.

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

During the past 4 weeks, how much difficulty did your child have	***Not Possible (Almost Impossible)***	***Very Difficult***	***Difficult***	***Slightly Difficult***	***Easy***	***Very Easy***	***No problem at all***
35. playing or spending time on their 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 relationship? (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 recreational activities? (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**

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SECTION 6: HEALTH

In the past 4 weeks,	*Admitted to hospital*	*5 or more visits*	*3 to 5 visits*	*Two visits*	*One visit*	*No visits*
44. How many times has your child had to visit the doctor or the hospital?	**0**	**1**	**2**	**3**	**4**	**5**

In the past 4 weeks,	*Very Poor*	*Poor*	*Fair*	*Good*	*Very Good*	*Excellent*
45. How would you rate your child's overall health?	**0**	**1**	**2**	**3**	**4**	**5**

46. List the medications and supplements (e.g., vitamin D, calcium, etc.) your child has been taking in the last 4 weeks

0. No medications / supplements

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

SECTION 7: YOUR OVERALL QUALITY OF LIFE

In the past 4 weeks,	*Very Poor*	*Poor*	*Fair*	*Good*	*Very Good*	*Excellent*
47. How would you rate your child's overall quality of life?	**0**	**1**	**2**	**3**	**4**	**5**

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SECTION 8: IMPORTANCE OF ITEMS TO YOUR QUALITY OF LIFE

Thinking about how your child is doing now for each of the items, how much of an <u>impact</u> does the item have on your <u>child's quality of life</u>?	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 vehicle	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 or fatigued easily	0	1	2	3	4
27. Feel tired during school or work	0	1	2	3	4
28. Feel tired during recreational activities	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. Lacking self-confidence	0	1	2	3	4
34. Being unable to focus or pay attention	0	1	2	3	4
35. Playing or spending time on their 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 relationship	0	1	2	3	4

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	None	A Little	Some	Quite a Bit	A Lot
40. Participating in hobbies with others	**0**	**1**	**2**	**3**	**4**
41. Participating in physical recreational activities	**0**	**1**	**2**	**3**	**4**
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 medications and supplements	**0**	**1**	**2**	**3**	**4**

SECTION 9: FACTS ABOUT YOUR CHILD

1. My child is a:	☐ **Male** ☐ **Female**
2. What is your child's date of birth?	_____ / _____ **Month Year**
3. What is the highest school grade your child has 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?** _____

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SECTION 10: FACTS ABOUT YOU

1. Are you:	☐ **Male** ☐ **Female**
2. What is your date of birth?	_____ / _____ **Month Year**
3. Which of the following best describes your current work status? (check all that apply)	**Not working due to my child's health** _____ **Not working for other reasons** _____ **Looking for work outside the home** _____ **Working full or part time (either outside the home or at a home based business)** _____ **Full time homemaker** _____
4. Which of the following best describes your relationship to your child?	**Biological Parent** _____ **Step Parent** _____ **Foster Parent** _____ **Adoptive Parent** _____ **Guardian** _____ **Professional caregiver** _____ **Other (please explain)** _____
5. On average, how many days per week are you responsible for care giving activities for your child?	_____ **days per week**
6. What is the highest level of school you have completed?	**Some high school or less** _____ **High school diploma/GED** _____ **Vocational school or some college** _____ **College or Undergraduate degree** _____ **Professional or Graduate degree** _____

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

THANK YOU FOR YOUR PARTICIPATION!

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