

CPCHILD™

Caregiver Priorities & Child Health Index of Life with Disabilities

Instructions

1. This questionnaire is about your child's health, comfort and well being, and about caring for his/her needs.
2. Please read the instructions 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:

LEVEL OF ASSISTANCE

Consider how each of the following activities is <u>usually</u> performed by/for your child.							T O T A L	M O D E R A T E	M I N I M A L / D	S U P E R V I S E D	I N D E P E N D E N T
Rate how <u>difficult</u> each of these activities were in the past 2 weeks, <u>and</u> choose the <u>level of assistance</u> that was required to help your child perform these activities.											
During the <u>past 2 weeks</u> , how difficult was the following:	Not Possible (Almost Impossible)	Very Difficult	Difficult	Slightly Difficult	Easy	Very Easy	No problem at all				
1. putting on / wearing footwear? (socks, shoes, braces, etc.)	0	1	2	3	4	5	6	0	1	2	3

In the above example, the task of putting on / wearing footwear was rated as *very easy*, and the child required a *minimal / supervised* level of assistance to put on footwear.

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.

Child's name: _____

Name of parent or caregiver completing form: _____

Date: _____

SECTION 1: PERSONAL CARE / ACTIVITIES OF DAILY LIVING

LEVEL OF ASSISTANCE

Consider how each of the following activities is <u>usually</u> performed by/for your child. Rate how <u>difficult</u> each of these activities were in the past 2 weeks, <u>and</u> choose the <u>level of assistance</u> that was required to help your child perform these activities.							T O T A L	M O D E R A T E	M I N I M A L / D	S U P E R V I S E D	I N D E P E N D E N T
During the <u>past 2 weeks</u>, how difficult was the following:	<i>Not Possible</i> (Almost Impossible)	<i>Very Difficult</i>	<i>Difficult</i>	<i>Slightly Difficult</i>	<i>Easy</i>	<i>Very Easy</i>					
1. eating/drinking or being fed? (in the usual way that it is done i.e. orally <u>or</u> by tube <u>or</u> both)	0	1	2	3	4	5	6	0	1	2	3
2. maintaining oral hygiene? (keeping mouth and teeth clean)	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? (bladder & bowel function, hygiene etc.)	0	1	2	3	4	5	6	0	1	2	3
5. changing diapers/underwear?	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, braces, etc.)	0	1	2	3	4	5	6	0	1	2	3
9. hair care (washing, drying, brushing/combing, braiding, etc.)	0	1	2	3	4	5	6	0	1	2	3
1A. other personal care activity? Specify: _____	0	1	2	3	4	5	6	0	1	2	3
1B. other personal care activity? Specify: _____	0	1	2	3	4	5	6	0	1	2	3

SECTION 2: POSITIONING, TRANSFERRING & MOBILITY

								LEVEL OF ASSISTANCE			
Consider how each of the following activities is <u>usually</u> performed by/for your child. Rate how <u>difficult</u> each of these activities were in the past 2 weeks, <u>and</u> choose the <u>level of assistance</u> that was required to help your child perform these activities.								T O T A L	M O D E R A T E	S U P E R V I S E / I N I T I A L	I N D E P E N D E N T
During the <u>past 2 weeks</u> , how difficult was:	Not Possible (Almost Impossible)	Very Difficult	Slightly Difficult	Easy	Very Easy	No problem at all					
10. getting in and out of bed?	0	1	2	3	4	5	6	0	1	2	3
11. transferring into/out of a wheelchair/chair?	0	1	2	3	4	5	6	0	1	2	3
12. sitting in a wheelchair/chair?	0	1	2	3	4	5	6	0	1	2	3
13. standing for exercise/transfers?	0	1	2	3	4	5	6	0	1	2	3
14. moving about in the home? (in whatever way possible)	0	1	2	3	4	5	6	0	1	2	3
15. moving about outdoors? (in whatever way possible)	0	1	2	3	4	5	6	0	1	2	3
16. getting in and out of a motor vehicle? (car, van or bus)	0	1	2	3	4	5	6	0	1	2	3
17. visiting public places? (park, theatre, sightseeing, 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 & EMOTIONS

During the <u>past 2 weeks</u> , how often did your child experience pain or discomfort							INTENSITY			
	<i>Every day</i>	<i>Very Often</i>	<i>Fairly Often</i>	<i>A few times</i>	<i>Once or twice</i>	<i>None of the time</i>	S E V E R E	M O D E R A T E	M I L D	N O N E
18. while eating/drinking or being fed? _____	0	1	2	3	4	5	0	1	2	3
19. during toileting? (bladder & bowel function, hygiene, diapering, etc.) _____	0	1	2	3	4	5	0	1	2	3
20. while dressing/undressing? _____	0	1	2	3	4	5	0	1	2	3
21. during transfers or position changes? _____	0	1	2	3	4	5	0	1	2	3
22. while seated? _____	0	1	2	3	4	5	0	1	2	3
23. while lying down in bed? _____	0	1	2	3	4	5	0	1	2	3
24. that disturbed your child's sleep? _____	0	1	2	3	4	5	0	1	2	3
3A. during other activity? Specify: _____ _____	0	1	2	3	4	5	0	1	2	3
3B. during other activity? Specify: _____ _____	0	1	2	3	4	5	0	1	2	3

During the <u>past 2 weeks</u> , how often was your child										
25. agitated, upset, or angry? _____	0	1	2	3	4	5	0	1	2	3
26. unhappy or sad? _____	0	1	2	3	4	5	0	1	2	3

SECTION 4: COMMUNICATION & SOCIAL INTERACTION

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 2 weeks.

During the <u>past 2 weeks</u> , how much difficulty did your child have	<i>Not Possible</i> (Almost Impossible)	<i>Very Difficult</i>	<i>Difficult</i>	<i>Slightly Difficult</i>	<i>Easy</i>	<i>Very Easy</i>	<i>No problem at all</i>
	0	1	2	3	4	5	6
27. understanding you? _____	0	1	2	3	4	5	6
28. being understood by you? _____	0	1	2	3	4	5	6
29. communicating with those who don't know your child well? _____	0	1	2	3	4	5	6
30. playing alone? _____	0	1	2	3	4	5	6
31. playing with others? _____	0	1	2	3	4	5	6
32. attending school/child care? _____	0	1	2	3	4	5	6
33. participating in recreational activities (swimming, interacting with family and friends, etc.)? _____	0	1	2	3	4	5	6
4A. other social activity? Specify: _____ _____	0	1	2	3	4	5	6
4B. other social activity? Specify: _____ _____	0	1	2	3	4	5	6

SECTION 5: HEALTH

In the past 2 weeks	<i>Please circle the option that fits best</i>					
34. How many times has your child had to visit the doctor or the hospital? 	<i>Admitted >7 days</i> 0	<i>Admitted < 7 days</i> 1	<i>3 or more times</i> 2	<i>Twice</i> 3	<i>Once</i> 4	<i>None</i> 5

In the past 2 weeks	<i>Very Poor</i>	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Very Good</i>	<i>Excellent</i>
35. How would you rate your child's overall health? 	0	1	2	3	4	5

36. List the medications your child has been taking in the last 2 weeks

0. No medications

1.

2.

3.

4.

5.

6.

7.

8.

9.

SECTION 6: YOUR CHILD'S OVERALL QUALITY OF LIFE

In the past 2 weeks	<i>Very Poor</i>	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Very Good</i>	<i>Excellent</i>
37. How would you rate your child's overall quality of life? 	0	1	2	3	4	5

SECTION 7: IMPORTANCE OF ITEMS TO YOUR CHILD'S QUALITY OF LIFE

How importantly do you think your child's current status with each item contributes towards his/her quality of life?	Least Important	Not Very Important	Slightly Important	Fairly Important	Very Important	Most Important
1. Eating / drinking or being fed	0	1	2	3	4	5
2. Maintaining oral hygiene	0	1	2	3	4	5
3. Bathing / washing	0	1	2	3	4	5
4. Toileting activities / hygiene	0	1	2	3	4	5
5. Changing diapers / underwear	0	1	2	3	4	5
6. Putting on/taking off upper clothing	0	1	2	3	4	5
7. Putting on/taking off lower clothing	0	1	2	3	4	5
8. Putting on / wearing footwear	0	1	2	3	4	5
9. Hair care / grooming	0	1	2	3	4	5
10. Getting in and out of bed	0	1	2	3	4	5
11. Transferring into / out of a wheelchair / chair	0	1	2	3	4	5
12. Sitting in a wheelchair / chair	0	1	2	3	4	5
13. Standing for exercise / transfers	0	1	2	3	4	5
14. Moving about indoors	0	1	2	3	4	5
15. Moving about outdoors	0	1	2	3	4	5
16. Getting in / out of a motor vehicle	0	1	2	3	4	5
17. Visiting public places	0	1	2	3	4	5
18. Comfort while feeding	0	1	2	3	4	5
19. Comfort during toileting activities	0	1	2	3	4	5
20. Comfort while dressing /undressing	0	1	2	3	4	5
21. Comfort during transfers or position changes	0	1	2	3	4	5
22. Comfort while sitting	0	1	2	3	4	5
23. Comfort while lying down	0	1	2	3	4	5
24. Comfort while sleeping	0	1	2	3	4	5
25. Emotional state or behavior	0	1	2	3	4	5
26. Happiness	0	1	2	3	4	5
27. Able to understand you	0	1	2	3	4	5
28. Able to be understood by you	0	1	2	3	4	5
29. Able to communicate with others	0	1	2	3	4	5
30. Able to play alone	0	1	2	3	4	5
31. Able to play with others	0	1	2	3	4	5
32. Able to attend school / child care	0	1	2	3	4	5
33. Able to participate in recreational activities	0	1	2	3	4	5
34. Minimizing doctor visits and hospitalization	0	1	2	3	4	5
35. Overall health	0	1	2	3	4	5
36. Minimizing number of medications	0	1	2	3	4	5

SECTION 8: 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 <u>highest</u> 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? _____

SECTION 9: 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 University degree ____ Professional or Graduate degree ____

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

THANK YOU FOR YOUR PARTICIPATION!