Parent Version	Study ID:	Date:

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:

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,

and choose the **level of assistance** that was required to help your child perform these activities.

Lastly, select **how important a goal** it is for your child to improve in each of the following activities.

During the past 2 weeks, how difficult was the following:	Not possible (almost impossible)	Very difficult	Difficult	Slightly difficult	Easy	Very easy	No problem at all	LEVEL OF ASSISTANCE: TOTAL	MODERATE	MINIMAL/SUPERVISED	INDEPENDENT	LEVEL OF IMPORTANCE: NOT IMPORTANT GOAL	SOMEWHAT IMPORTANT GOAL	VERY IMPORTANT GOAL
1. putting on/ wearing footwear? (socks, shoes, braces, etc.) _____	0	(1)	2	3	4	5	6	(0)	1	2	3	0	1	(2)

In the above example, the task of putting on / wearing footwear was rated as *very difficult*, and the child required *total* assistance to put on footwear. Additionally, the parent rated putting on footwear as a *very important* goal to improve.

SECTION 1: PERSONAL CARE / ACTIVITIES OF DAILY LIVING

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,

and choose the **level of assistance** that was required to help your child perform these activities.

Lastly, select **how important a goal** it is for your child to improve in each of the following activities.

During the past 2 weeks, how difficult was the following:	Not possible (almost impossible)	Very difficult	Difficult	Slightly difficult	Easy	Very easy	No problem at all	LEVEL OF ASSISTANCE: TOTAL	MODERATE	MINIMAL/SUPERVISED	INDEPENDENT	LEVEL OF IMPORTANCE: NOT IMPORTANT GOAL	SOMEWHAT IMPORTANT GOAL	VERY IMPORTANT GOAL
1. Eating/drinking or being fed? (in the usual way that it is done i.e. orally or by tube or both)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
2. Maintaining oral hygiene? (keeping mouth and teeth clean)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
3. Bathing / washing?	0	1	2	3	4	5	6	0	1	2	3	0	1	2
4. Toileting activities? (bladder & bowel function, hygiene etc)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
5. Changing diapers/underwear?	0	1	2	3	4	5	6	0	1	2	3	0	1	2
6. Putting on/taking off upper body clothing? (shirt, jacket, etc)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
7. Putting on/taking off lower body clothing? (pants, etc)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
8. Putting on/wearing footwear? (socks, shoes, braces, etc)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
9. Hair care? (washing, drying, brushing/combing, braiding, etc)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
1A. Other personal care activity? Specify:_____	0	1	2	3	4	5	6	0	1	2	3	0	1	2

1B. Other personal care activity? Specify:_____	0	1	2	3	4	5	6		0	1	2	3		0	1	2
	_____															

SECTION 2: POSITIONING, TRANSFERRING & MOBILITY

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,

and choose the **level of assistance** that was required to help your child perform these activities.

Lastly, select **how important a goal** it is for your child to improve in each of the following activities.

During the past 2 weeks, how difficult was the following:	Not possible (almost impossible)	Very difficult	Difficult	Slightly difficult	Easy	Very easy	No problem at all	LEVEL OF ASSISTANCE: TOTAL	MODERATE	MINIMAL/SUPERVISED	INDEPENDENT	LEVEL OF IMPORTANCE: NOT IMPORTANT GOAL	SOMEWHAT IMPORTANT GOAL	VERY IMPORTANT GOAL
10. Getting in and out of bed?	0	1	2	3	4	5	6	0	1	2	3	0	1	2
11. Transferring into/out of a wheelchair/chair?	0	1	2	3	4	5	6	0	1	2	3	0	1	2
12. Sitting in a wheelchair/chair?	0	1	2	3	4	5	6	0	1	2	3	0	1	2
13. Standing for exercise/transfers?	0	1	2	3	4	5	6	0	1	2	3	0	1	2
14. Moving about in the home? (in whatever way possible)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
15. Moving about outdoors? (in whatever way possible)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
16. Getting in and out of a motor vehicle? (car, van, or bus)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
17. Visible public places? (park, theatre, sightseeing, etc.)	0	1	2	3	4	5	6	0	1	2	3	0	1	2
2A. Other activity? Specify:_____	0	1	2	3	4	5	6	0	1	2	3	0	1	2
	_____													

2B. Other activity? **Specify:_____**	0	1	2	3	4	5	6	0	1	2	3	0	1	2
	_____													

SECTION 3: COMFORT & EMOTIONS

Indicate how **<u>often</u>** your child experienced pain or discomfort in the past 2 weeks,

<u>and</u> choose the **<u>level of intensity</u>** of the pain or discomfort your child experienced.

Lastly, select **<u>how important a goal</u>** it is for your child to improve their pain or discomfort in each area.

During the <u>past 2 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	INTENSITY: MODERATE	INTENSITY: MILD	INTENSITY: NONE	LEVEL OF IMPORTANCE: NOT IMPORTANT GOAL	LEVEL OF IMPORTANCE: SOMEWHAT IMPORTANT GOAL	LEVEL OF IMPORTANCE: VERY IMPORTANT GOAL
18. While eating/drinking or being fed?	0	1	2	3	4	5	0	1	2	3	0	1	2
19. During toileting? (bladder & bowel function, hygiene, diapering, etc.)	0	1	2	3	4	5	0	1	2	3	0	1	2
20. While dressing/undressing?	0	1	2	3	4	5	0	1	2	3	0	1	2
21. During transfers or position changes?	0	1	2	3	4	5	0	1	2	3	0	1	2
22. While seated?	0	1	2	3	4	5	0	1	2	3	0	1	2
23. While lying down in bed?	0	1	2	3	4	5	0	1	2	3	0	1	2
24. That disturbed your child's sleep?	0	1	2	3	4	5	0	1	2	3	0	1	2
3A. During other activity? **Specify:_____**	0 _____	1	2	3	4	5	0	1	2	3	0	1	2
3B. During other activity? **Specify:_____**	0 _____	1	2	3	4	5	0	1	2	3	0	1	2

Rate how **<u>often</u>** your child experienced negative emotions in the past 2 weeks,

<u>and</u> choose the **<u>level of intensity</u>** of the negative emotions your child experienced.

Lastly, select **<u>how important a goal</u>** it is for your child to improve in each of the following activities.

During the <u>past 2 weeks</u>, how often was your child:	Everyday	Very often	Fairly often	A few times	Once or twice	None of the time	INTENSITY: SEVERE	INTENSITY: MODERATE	INTENSITY: MILD	INTENSITY: NONE	LEVEL OF IMPORTANCE: NOT IMPORTANT GOAL	LEVEL OF IMPORTANCE: SOMEWHAT IMPORTANT GOAL	LEVEL OF IMPORTANCE: VERY IMPORTANT GOAL
25. Agitated, upset, or angry?	0	1	2	3	4	5	0	1	2	3	0	1	2
26. Unhappy or sad?	0	1	2	3	4	5	0	1	2	3	0	1	2

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.

Lastly, select **how important a goal** it is for your child to improve in each area.

During the past 2 weeks, how much difficulty did your child have:	Not possible (almost impossible)	Very difficult	Difficult	Slightly difficult	Easy	Very easy	No problem at all	LEVEL OF IMPORTANCE: NOT IMPORTANT GOAL	SOMEWHAT IMPORTANT GOAL	VERY IMPORTANT GOAL
27. Understanding you?	0	1	2	3	4	5	6	0	1	2
28. Being understood by you?	0	1	2	3	4	5	6	0	1	2
29. Communicating with those who don't know your child well?	0	1	2	3	4	5	6	0	1	2
30. Playing alone?	0	1	2	3	4	5	6	0	1	2
31. Playing with others?	0	1	2	3	4	5	6	0	1	2
32. Attending school/child care?	0	1	2	3	4	5	6	0	1	2
33. Participating in recreational activities (swimming, interacting with family and friends, etc.)?	0	1	2	3	4	5	6	0	1	2
4A. Other social activity? Specify:_____	0	1	2	3	4	5	6 _____	0	1	2
4B. Other social activity? Specify:_____	0	1	2	3	4	5	6 _____	0	1	2

SECTION 5: HEALTH

Indicate the **number of times** your child has visited the doctor in the past 2 weeks, **and how important a goal** it is for your child to **minimize the number of doctors' visits and hospitalizations**.	Admitted >7 days	Admitted <7 days	3 or more times	Twice	Once	None	LEVEL OF IMPORTANCE: NOT IMPORTANT GOAL	SOMEWHAT IMPORTANT GOAL	VERY IMPORTANT GOAL
34. How many times has your child had to visit the doctor or the hospital?	0	1	2	3	4	5	0	1	2

Rate your child's **overall health** in the past 2 weeks, **and how important a goal** it is for your child to **improve their overall health**.	Very poor	Poor	Fair	Good	Very good	Excellent	LEVEL OF IMPORTANCE		
35. How would you rate your child's overall health?	0	1	2	3	4	5	0	1	2

	LEVEL OF IMPORTANCE		
Rate how important it is to your child`s quality of life to minimize the number of medications they take.	NOT IMPORTANT GOAL	SOMEWHAT IMPORTANT GOAL	VERY IMPORTANT GOAL

	0	1	2

36. List the medications your child has been taking in the last 2 weeks <u>AND</u> please rate how important of a goal it is to minimize the number of medications they take.

0. **No medications** ☐	
1.	6.
2.	7.
3.	8.
4.	9.
5.	10.

SECTION 6: YOUR CHILD'S OVERALL QUALITY OF LIFE

							LEVEL OF IMPORTANCE		
Rate your child's **overall quality of life** in the past 2 weeks, **<u>and</u> <u>how important a goal</u>** it is for your child to **improve their overall quality of life**.							NOT IMPORTANT GOAL	SOMEWHAT IMPORTANT GOAL	VERY IMPORTANT GOAL
	Very poor	Poor	Fair	Good	Very good	Excellent			
37. How would you rate your child's overall quality of life?	0	1	2	3	4	5	0	1	2

SECTION 7: FACTS ABOUT YOUR CHILD

1. My child is:	☐ 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? _____

SECTION 8: FACTS ABOUT YOU

1. You are	☐ Male ☐ Female ☐ _____
2. What is your child's 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 <u>this</u> <u>questionnaire</u> <u>only</u> (in minutes): _____

THANK YOU FOR YOUR PARTICIPATION!

