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Caregiver Priorities & Child Health Index of Life with Disabilities

Instructions

1. This questionnaire is about your health, comfort and well being, and about caring for your 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 you **usually** perform each of the following activities.

Rate how **difficult** each of these activities were in the past 2 weeks,

and choose the **level of assistance** you required to help you perform these 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
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 you 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 comfort and well being.

Your name: ____

Date: ____

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SECTION 1: PERSONAL CARE / ACTIVITIES OF DAILY LIVING

LEVEL OF ASSISTANCE

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

Rate how **difficult** each of these activities were in the past 2 weeks,

and choose the **level of assistance** you required to help you perform these 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*	TOTAL	MODERATE	MINIMAL / SUPERVISED	INDEPENDENT
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
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

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SECTION 2: POSITIONING, TRANSFERRING & MOBILITY

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

Rate how **difficult** each of these activities were in the past 2 weeks,

and choose the **level of assistance** you required to help you perform these activities.

During the past 2 weeks, how difficult was:	*Not Possible (Almost Impossible)*	*Very Difficult*	*Difficult*	*Slightly Difficult*	*Easy*	*Very Easy*	*No problem at all*	LEVEL OF ASSISTANCE: TOTAL	MODERATE	MINIMAL / SUPERVISED	INDEPENDENT
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

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SECTION 3: COMFORT & EMOTIONS

During the past 2 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*	INTENSITY: SEVERE	MODERATE	MILD	NONE
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 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 past 2 weeks, how often were you										
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

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SECTION 4: COMMUNICATION & SOCIAL INTERACTION

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

Rate how **difficult** each of these activities were in the past 2 weeks

During the past 2 weeks, how much difficulty did you have	*Not Possible (Almost Impossible)*	*Very Difficult*	*Difficult*	*Slightly Difficult*	*Easy*	*Very Easy*	*No problem at all*
27. understanding your parent/ caregiver?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
28. being understood by your parent/ caregiver?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
29. communicating with those who don't know you 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**

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SECTION 5: HEALTH

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

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

36. List the medications you have been taking in the last 2 weeks

0. No medications

1. ______________________________

2. ______________________________

3. ______________________________

4. ______________________________

5. ______________________________

6. ______________________________

7. ______________________________

8. ______________________________

9. ______________________________

SECTION 6: YOUR OVERALL QUALITY OF LIFE

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

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SECTION 7: IMPORTANCE OF ITEMS TO YOUR QUALITY OF LIFE

How importantly do you think your current status with each item contributes towards your 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 caregiver	0	1	2	3	4	5
28. Able to be understood by caregiver	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

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SECTION 8: FACTS ABOUT YOU

1. Are you:	☐ **Male** ☐ **Female**
2. What is your date of birth?	**_____ / _____ / _____** **Month Day Year**
3. What is the <u>highest</u> 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 <u>this</u> <u>questionnaire</u> <u>only</u> (in units of time):_______________

THANK YOU FOR YOUR PARTICIPATION!

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