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# 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:**

<table>
<tr><td colspan="8">Consider how each of the following activities is usually performed by/for your child.<br>Rate how difficult each of these activities were in the past 2 weeks,<br>and choose the level of assistance that was required to help your child perform these activities.</td><td colspan="4">LEVEL OF ASSISTANCE</td></tr>
<tr><td>During the past 2 weeks, how difficult was the following:</td><td>Not Possible (Almost Impossible)</td><td>Very Difficult</td><td>Difficult</td><td>Slightly Difficult</td><td>Easy</td><td>Very Easy</td><td>No problem at all</td><td>TOTAL</td><td>MODERATE</td><td>MINIMAL / SUPERVISED</td><td>INDEPENDENT</td></tr>
<tr><td>1. putting on / wearing footwear? (socks, shoes, braces, etc.)</td><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>(5)</td><td>6</td><td>0</td><td>1</td><td>(2)</td><td>3</td></tr>
</table>

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: ______________________________

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## 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.

| 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. 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 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.

| 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 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 |
|---|---|---|---|---|---|---|---|---|---|---|
| **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 past 2 weeks, 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 |

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## 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 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* |
|---|---|---|---|---|---|---|---|
| **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** |

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## SECTION 5: HEALTH

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

| In the past 2 weeks | *Very Poor* | *Poor* | *Fair* | *Good* | *Very Good* | *Excellent* |
|---|---|---|---|---|---|---|
| **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 | *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** |

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## 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 |



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## SECTION 8: FACTS ABOUT YOUR CHILD

| | |
|---|---|
| **1. My child is a:** | ☐ **Male** ☐ **Female** |
| **2. What is your child's date of birth?** | _____ / _____ / _____<br>**Month Day Year** |
| **3. What is the <u>highest</u> school grade your child has completed? (check only one grade)** | **Preschool** ___<br>**Kindergarten** ___<br>**1st Grade** ___<br>**2nd Grade** ___<br>**3rd Grade** ___<br>**4th Grade** ___<br>**5th Grade** ___<br>**6th Grade** ___<br>**7th Grade** ___<br>**8th Grade** ___<br>**9th Grade** ___<br>**10th Grade** ___<br>**11th Grade** ___<br>**12th Grade** ___<br>**Ungraded** ___<br><br>**If ungraded, how many years attended?** _____ |

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## SECTION 9: FACTS ABOUT YOU

| | |
|---|---|
| **1. Are you:** | ☐ **Male** ☐ **Female** |
| **2. What is your date of birth?** | **_____ / _____ / _____**<br>**Month Day Year** |
| **3. Which of the following best describes your current work status? (check all that apply)** | **Not working due to my child's health _____**<br>**Not working for other reasons _____**<br>**Looking for work outside the home _____**<br>**Working full or part time (either outside the home or at a home based business) _____**<br>**Full time homemaker _____** |
| **4. Which of the following best describes your relationship to your child?** | **Biological Parent _____**<br>**Step Parent _____**<br>**Foster Parent _____**<br>**Adoptive Parent _____**<br>**Guardian _____**<br>**Professional caregiver _____**<br>**Other (please explain)**<br>**_________________________** |
| **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 _____**<br>**High school diploma/GED _____**<br>**Vocational school or some college _____**<br>**College or University degree _____**<br>**Professional or Graduate degree _____** |

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

**THANK YOU FOR YOUR PARTICIPATION!**



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