About your child…

1) For **each** of the following activities, please tick one of the spaces to indicate how much help you would normally give to your child to complete that activity.

<table>
<thead>
<tr>
<th>Activity</th>
<th>No help given</th>
<th>Prompting only, no help</th>
<th>Some help/supervision given</th>
<th>Has to be done for him/her</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Washing hands</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Eating a bowl of cereal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Putting on a vest/T-shirt</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Getting out of bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Getting out of the bath</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Going to the toilet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Getting in and out of a car</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. Doing up buttons or buckles</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Picking up something from the floor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. Carrying a drink across the room</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Each item scored as follows*  
0 1 2 4

2) How many times have you got up for your child during the night over the last week?  
*(Please circle one of the following)*

<table>
<thead>
<tr>
<th>0 1–3 4–7 8–10 11+</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>
3) How many times has your child seen his or her friends outside of school hours over the past week?
   (Please circle one of the following)

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1–3</th>
<th>4–7</th>
<th>8–10</th>
<th>11+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

4) Many children squabble or quarrel with their friends or their brothers and sisters when they are playing together.
   Please tick one response which you feel best fits your child:
   [i] gets on well with other children; any squabbles or quarrels are trivial
   [ii] moderate difficulties when playing with other children; activities are often disrupted
   [iii] virtually never plays with other children without quarrelling

5) Apart from watching TV, did your child settle down to playing with any games or toys yesterday (with or without you or other children)?
   Please tick one of the following:
   [i] played well for more than an hour
   [ii] played for between half an hour and one hour
   [iii] played between fifteen minutes and half an hour
   [iv] played for fifteen minutes or less
   [v] did not play at all

6) How much time did your child spend yesterday occupying himself/herself (alone in a room, while you were in another room) without you going in to check on him/her?
   Please tick one of the following:
   [i] more than an hour
   [ii] between thirty minutes and one hour
   [iii] between fifteen minutes and thirty minutes
   [iv] for fifteen minutes or less
   [v] unable to leave even for a moment

7) Most children are sometimes difficult to manage. They can have temper tantrums or their behaviour can be difficult in other ways. In the last month, has your child been difficult to manage or control, at home or elsewhere?
   Please tick one of the responses which best fits your child:
   [i] usually easy to manage and control
   [ii] sometimes difficult to manage but for short periods only (less than 10 minutes)
   [iii] sometimes difficult to manage for longer periods
   [iv] often difficult to manage for prolonged or very frequent periods
   [v] very difficult; often needs two adults to manage

8) Children have many different ways of communicating. Some children use language (verbal) and others rely more on gestures (such as pointing or signing or the look on their face; non-verbal). Please circle one answer which you feel is how your child mostly communicates:
9) Please tick one of the following responses which best fits how your child communicates (verbal or non-verbal):
   [i] communicates easily all the time with adults and other children 0
   [ii] only communicates with people who know him/her very well 2
   [iii] only communicates things such as pleasure, a greeting or if he/she wants or needs something 4

10) Sometimes children can be very noisy. In the last week, has your child made loud noises? Please tick one of the following:
   [i] never makes a noise 1
   [ii] noisy, but no more than other children 0
   [iii] occasional outbursts of loud screaming or shouting 2
   [iv] loud screaming at least once a day for more than ten minutes 3
   [v] frequent attacks of almost continuous screaming, lasting more than one hour 4

11) How many items of special equipment does your child need at home or at school which are essential for him/her? (Special equipment includes splints, callipers, hearing aids, feeding tubes, food processors, lifts and hoists, wheelchairs, ramps, suction equipment, nebulisers, catheters, oxygen, body supports etc.) Please circle one of the following:

   0  1 – 3  4 – 7  8 – 10  11+
   0  1  2  3  4

12) How many times did you need to lift your child (with or without a hoist) on the last occasion you spent a full day with him/her? Please circle one of the following:

   0  1 – 4  5 – 10  11 – 15  16+
   0  1  2  3  4

About your family…..

13) Have you had to change your work situation because of your child’s condition? Please tick one response which best fits your situation:
   [i] no effect on my work 0
   [ii] some effect on my work; I occasionally need to take time off and lose pay, or cannot work as many hours as I would like 2
   [iii] I have had to stop working 4

14) How many times did you give your child some treatment, medicine or therapy at home on the last occasion you spent a full day with him/her? (This includes giving medicine or pills or injecting drugs, physiotherapy, preparing food in a special way, feeding by tube, giving suction etc.). Please circle one of the following:
15) Do you have any difficulties organising outings or holidays as a family because of your child’s condition?

Yes  Sometimes  No

4  2  0

16) Do you think that the demands of caring for your child have placed any extra stress on your other children? Please circle one of the following:

None  Slight  Moderate  Severe  No other children in the family

0  1  2  4  0

17) Do you think that the difficulties resulting from your child’s condition restrict your social life in any way? Please circle one of the following:

Yes  Sometimes  No

4  2  0

18) Do you think that the demands of caring for your child has placed any extra stress on you as a parent/carer? Please circle one of the following:

None  Slight  Moderate  Severe

0  1  2  4

About your home…..

19) Has your present home been adapted in any way over the last year to help your child? Please circle one of the following:

YES  NO

If Yes, how many adaptations have been made? (Please circle one of the following)

1 – 3  4 – 7  8 – 10  11 +

1  2  3  4

20) Are new adaptations planned or considered necessary for the future? Please circle one of the following:

0  1 – 3  4 – 7  8 – 10  11+

0  1  2  3  4
21) a. How many rooms (excluding halls and passages) are there in your home?

Number of rooms: .................................................................

b. **Over the past week**, how many of these did your child go into?

Number of my rooms my child has entered: ...............................  

c. How many of these did your child go into without help from you or another person?

Number of rooms my child entered without help: ..........................

**ACCESS 1**: Calculate by using the values given for 21a and 21b as follows:

Multiply 21b by 100 and divide by 21a, then score as follows:

- 100 = 0
- 75-99 = 1
- 50-74 = 2
- 25-49 = 3
- 0-24 = 4

**ACCESS 2**: Calculate by using the values given at 21b and 21c as follows:

If 21c = 0, score 4. If 21c ≥ 1 or more, multiply 21c by 100 and divide by 21b, then score as follows:

- 100 = 0
- 75-99 = 1
- 50-74 = 2
- 25-49 = 3
- 0-24 = 4

**Getting out and about.....**

22) How many times has your child left your home (to go to the shops or down the street) without an adult **over the past week**?

Please circle one of the following:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1 – 7</th>
<th>8 – 13</th>
<th>14 – 20</th>
<th>21+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
23) Excluding trips to and from school/nursery, how many times has your child been on a longer outing over the past week which required some form of transport? Please circle one of the following:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1 – 3</th>
<th>4 – 7</th>
<th>8 – 10</th>
<th>11+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

24) What is the furthest distance your child has gone outside without your help over the past week? Please circle one of the following:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1 – 100 yards</th>
<th>101 – 440 yards</th>
<th>¼ - ½ mile</th>
<th>more than ½ mile</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

25) Approximately how long does it take for your child to travel from home to school? (Please circle one of the following)

<table>
<thead>
<tr>
<th></th>
<th>0-15 mins</th>
<th>16-30 mins</th>
<th>31-45 mins</th>
<th>46 mins-1 hour</th>
<th>more than 1 hour</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

26) How many out of school activities (such as sports, music lessons, scouts/brownies, clubs etc.) did your child do in the last week? Please circle one of the following:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1 – 2</th>
<th>3+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

Going to school.....

27) Do you think that your child is at the right school for him/her? Please circle one of the following:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not perfect, but best available</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

28) How many days of school did your child miss in the last month (during a school term)? Please circle one of the following:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1 – 3</th>
<th>4 – 10</th>
<th>11+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>
The cost of looking after a child.....

29) Would you say that your child's difficulties mean that you as a family have financial problems?
   Yes  No
   0

   If Yes, would you say these were:

<table>
<thead>
<tr>
<th></th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

Contact with services and people.....

30) In the last month, how many visits have you had at home from professionals involved with your child (such as health visitor, community nurse, social worker, home help etc.)? Please circle one of the following:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1-4</th>
<th>5-8</th>
<th>9-12</th>
<th>13+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

31) In the last month, how often have you had to make contact with professionals (by phone or by letter) to ask them for help because of your child's difficulties? Please circle one of the following:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1-4</th>
<th>5-8</th>
<th>9-12</th>
<th>13+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

32) Do you find it difficult getting the right care for your child?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

Family and friends.....

33) Do you think that society in general (such as strangers, public services etc.) is supportive and understanding where your child is concerned?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

34) Do you think people in your area are generally supportive and understanding where your child is concerned?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>
35) Can you get a break from caring for your child if you need it?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

**Scoring procedure**

Create a **raw score** by summating the scores for the items pertaining to each domain as follows:

- **Communication**
  - Items: 8, 9

- **Mobility**
  - Items: 1d, 1i, 11, 12, 19, 20, ACCESS 1, ACCESS 2

- **Self care**
  - Items: 1a, 1c, 1e, 1f, 1g, 1j

- **Domestic life**
  - Items: 1b, 14, 28, 29, 30, 31

- **Interpersonal interactions** and **relationships**
  - Items: 1h, 2, 3, 7, 10, 16, 22, 23, 24, 26

- **Community and social life**
  - Items: 4, 5, 6, 13, 15, 17, 18, 25, 27, 32, 33, 34, 35

Convert this into a **domain score** (out of 100), which is comparable between domains, by multiplying the **raw score** for each domain by the appropriate constant:

- **Communication**: 12.50
- **Mobility**: 3.12
- **Self care**: 4.17
- **Domestic life**: 4.17
- **Interpersonal interactions** and **relationships**: 2.50
- **Community and social life**: 1.92