

About this questionnaire

Every child is different, and parents or carers have different experiences and opinions. It is important that we find out from parents themselves what it is like to bring up and care for a child, particularly if your child has some sort of problems.

These questions are all about everyday life which you and your child experience. They should help us to find out if you have any difficulties, and how severe they are.

I have tried to make filling in this questionnaire as simple as possible. You should only tick **one** answer to each question. It will tell you in the question what to do.

There are also spaces for your comments, and I am very interested in what you have to say.

It should take no more than 20 minutes to fill in the questionnaire.

Thank you!



Name of your child:

Sex of your child:

Date of birth of your child:

Address your child lives at:

.....

.....

What is your relationship to the child?:

.....

About your child

These questions are about your child and the ways in which you look after him/her.

If your child has any sort of problem, please state the diagnosis which you have been given or tell me in your own words what is wrong with 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.

	No help given	Prompting only, no help	Some help/supervision given	Has to be done for him/her
Washing hands	_____	_____	_____	_____
Eating a bowl of cereal	_____	_____	_____	_____
Putting on a vest/T-shirt	_____	_____	_____	_____
Getting out of bed	_____	_____	_____	_____
Getting out of the bath	_____	_____	_____	_____
Going to the toilet	_____	_____	_____	_____
Getting in and out of a car	_____	_____	_____	_____
Doing up buttons or buckles	_____	_____	_____	_____
Picking up something from the floor	_____	_____	_____	_____
Carrying a drink across the room	_____	_____	_____	_____

2. How many times have you got up for your child during the night **over the last week?**

(Please circle **one** of the following)

0 1 – 3 4 – 7 8 – 10 11+



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)

0 1 – 3 4 – 7 8 – 10 11+

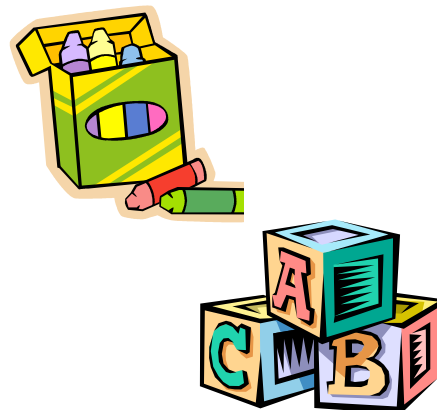
4. Many children squabble or quarrel with their friends or their brothers and sisters when they are playing together. Please tick **one** response which you feel best fits your child:

- [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:

Verbal Non-verbal Both verbal and non-verbal

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
- [ii] only communicates with people who know him/her very well
- [iii] only communicates things such as pleasure, a greeting or if he/she wants or needs something

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
- [ii] noisy, but no more than other children
- [iii] occasional outbursts of loud screaming or shouting
- [iv] loud screaming at least once a day for more than ten minutes
- [v] frequent attacks of almost continuous screaming, lasting more than one hour

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+



12. How many times did you need to lift you 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+

About your family

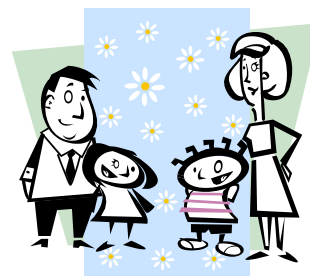
The following questions are about you and other members of your family, including any other children you may have.

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

[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

[iii] I have had to stop working



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:

0

1 – 4

5 – 8

9 – 12

13+



15. Do you have any difficulties organising outings or holidays as a family because of your child's condition?

Yes

Sometimes

No

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**

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

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

About your home

These questions are about your home and the things in your home which make looking after your child easier or more difficult.

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+

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+

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:

Getting out and about

These questions are about how you and your child get around, and about your child's friends and activities outside your home.

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:

0 1 – 7 8 – 13 14 – 20 21+

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:



0 1 – 3 4 – 7
8 – 10 11+

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

0 1 – 100 yards 101 – 440 yards ¼ - ½ mile more than ½ mile

25. Approximately how long does it take for your child to travel from home to school?

(Please circle **one** of the following)

0-15 mins 16-30 mins 31-45 mins
46 mins-1 hour more than 1 hour

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:



0 1 – 2 3+

Going to school

These questions are about your child's school and how you feel about it

Please tell me the name of your child's school, and describe in your own words what sort of a school it is.



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

Yes **No** **Not perfect, but best available**

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

0 **1 – 3** **4 – 10** **11+**

The cost of looking after a child

Looking after children always means extra costs for families, particularly if a child has a disability or other problems. These questions are about the extra costs you may have and how you pay for them.

29. Would you say that your child's difficulties mean that you as a family have financial problems?

Yes **No**



If **Yes**, would you say these were:

Mild **Moderate** **Severe**

Contact with services and people

These questions are about the people that you as a parent may see about your child. We would like to know whom you see and how much of your time is taken up with meeting them.

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:

0	1 – 4	5 – 8
9 12	13+	

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:

0	1 – 4	5 – 8
9 12	13+	



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

Yes	No	Sometimes
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Family and friends

These final questions are about people who may support you in caring for your child.

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

Yes	No	Sometimes
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34. Do you think people in your area are generally supportive and understanding where your child is concerned?

Yes	No	Sometimes
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35. Can you get a break from caring for your child if you need it?

Yes	No	Sometimes
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Thank you for taking time to fill in this questionnaire