
Managing Behaviour and Sleep Problems in Disabled Children: An Investigation into the Effectiveness and Costs of Parent-Training Interventions

Annex Survey Instruments and Recruitment Materials

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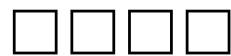
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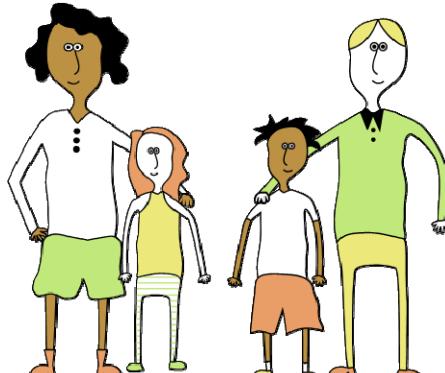
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Annex A

Quantitative Research Tools



The SPaR Project



The Supporting Parents Research Project

Questionnaire Booklet 1

Thank you very much for taking the time to fill in this booklet. It is all about your child, their behaviour and being a parent of a child with additional needs (such as learning difficulties, autistic spectrum conditions or physical disabilities).

On the last page is a consent form. This is to show that you are happy for *[service provider]* to give us your questionnaire and for you to take part in our research. Once received it will be detached from the rest of the booklet and stored separately.

PLEASE NOTE: If you are not the child's parent or primary carer, you do not need to complete this questionnaire booklet.

This booklet should take no longer than 20 minutes to fill in. Here are some instructions about how to complete it:

- Please answer questions as directed to. Then please complete the consent form on pages 11 and 12.
- Please answer the questions for the child for whom you are seeking help with their behaviour.
- If you have more than one child with additional needs and behaviour difficulties, please answer these questions for the child who has the most behaviour problems.

Once you have filled in the questionnaire, please return in the pre-paid envelope provided.

If you need any help filling in the questionnaire or have any questions, please contact Lucy Stuttard: 01904 321965, or write to her at: Social Policy Research Unit, University of York, York, YO10 5DD. Email: lcs500@york.ac.uk.

Why I have come along to the [name of intervention] group?

Please tell us up to three things you hope to achieve by coming along to the [name of intervention] group.

My first goal: _____

This is where I am now with this goal (*please circle one*):

Very far from
this goal 1 2 3 4 5 6 7 8 9 10 I have achieved
my goal

My second goal: _____

This is where I am now with this goal (*please circle one*):

Very far from
this goal 1 2 3 4 5 6 7 8 9 10 I have achieved
my goal

My third goal: _____

This is where I am now with this goal (*please circle one*):

Very far from
this goal 1 2 3 4 5 6 7 8 9 10 I have achieved
my goal

These first questions describe different children's behaviours. For each phrase please tick in the box (on the left) that best describes how often the behaviour currently occurs with your child, then tick the circle under "yes" or "no" (on the right) to show whether the behaviour is currently a problem for you. If any of these items are not applicable to your child (eg item 1 because your child is unable to dress themselves, or items 25 and 27 because your child does not have any brothers or sisters), please tick the 'Never' column.



This is how often my child behaves like this

Is this behaviour
a problem for
you?

Never	Seldom	Some-times	Often	Always	Yes	No			
1	2	3	4	5	6	7			
<input type="checkbox"/>	1. Dawdles in getting dressed	<input type="circle"/>	<input type="circle"/>						
<input type="checkbox"/>	2. Dawdles or lingers at mealtimes	<input type="circle"/>	<input type="circle"/>						
<input type="checkbox"/>	3. Has poor table manners	<input type="circle"/>	<input type="circle"/>						
<input type="checkbox"/>	4. Refuses to eat food presented	<input type="circle"/>	<input type="circle"/>						
<input type="checkbox"/>	5. Refuses to do chores when asked	<input type="circle"/>	<input type="circle"/>						
<input type="checkbox"/>	6. Slow in getting ready for bed	<input type="circle"/>	<input type="circle"/>						
<input type="checkbox"/>	7. Refuses to go to bed on time	<input type="circle"/>	<input type="circle"/>						
<input type="checkbox"/>	8. Does not obey house rules on own	<input type="circle"/>	<input type="circle"/>						

Please remember to tick a box on the left and a circle on the right for each question

This is how often my child behaves like this							Is this behaviour a problem for you?		
Never	Seldom	Some-times	Often	Always			Yes	No	
1	2	3	4	5	6	7			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9. Refuses to obey until threatened with punishment	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10. Acts defiant when told to do something	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11. Argues with parents about rules	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	12. Gets angry when doesn't get own way	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	13. Has temper tantrums	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	14. Sasses adults (answers back)	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	15. Whines	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	16. Cries easily	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	17. Yells or screams	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	18. Hits parents	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	19. Destroys toys or other objects	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	20. Is careless with toys or other objects	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	21. Steals	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	22. Lies	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	23. Teases or provokes other children	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	24. Verbally fights with friends own age	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	25. Verbally fights with sisters/brothers	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	26. Physically fights with friends own age	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	27. Physically fights with sisters/brothers	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	28. Constantly seeks attention	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	29. Interrupts	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	30. Is easily distracted	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	31. Has short attention span	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	32. Fails to finish tasks or projects	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	33. Has difficulty entertaining self alone	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	34. Has difficulty concentrating on one thing	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	35. Is overactive or restless	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	36. Wets the bed	<input type="radio"/>	<input type="radio"/>

Please remember to tick a box on the left and a circle on the right for each question

These next questions are about how people feel about being a parent. Below are things that parents have said about being a parent. For each statement, please tick the box which shows how much you agree or disagree with it.



	Strongly agree	Agree	Slightly agree	Slightly disagree	Disagree	Strongly disagree
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child. I have acquired this understanding	<input type="checkbox"/>					
2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age	<input type="checkbox"/>					
3. I go to bed the same way I wake up in the morning, feeling I have not accomplished much	<input type="checkbox"/>					
4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated	<input type="checkbox"/>					
5. My mother/father was better prepared to be a good mother/father than I am	<input type="checkbox"/>					
6. I would make a fine model for a new mother/father to follow so that she/he could learn to be a good parent	<input type="checkbox"/>					
7. Being a good parent is manageable, and any problems are easily solved	<input type="checkbox"/>					
8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one	<input type="checkbox"/>					
9. Sometimes I feel like I'm not getting anything done as a parent	<input type="checkbox"/>					
10. I meet my own personal expectations in my ability to care for my child	<input type="checkbox"/>					
11. If anyone can find the answer to what is troubling my child, I am the one	<input type="checkbox"/>					

	Strongly agree	Agree	Slightly agree	Slightly disagree	Disagree	Strongly disagree
12. My talents and interests are in other areas, not in being a parent	<input type="checkbox"/>					
13. Considering how long I've been a mother/father, I feel thoroughly familiar with this role	<input type="checkbox"/>					
14. If being a mother/father of a child were only more interesting, I would try harder to do a good job as a parent	<input type="checkbox"/>					
15. I honestly believe that I have all the skills necessary to be a good mother/father to my child	<input type="checkbox"/>					
16. Being a parent makes me tense and anxious	<input type="checkbox"/>					

These questions are about your child and also how you are managing your child's behaviour. For each statement can you please tick the box which shows how much you agree or disagree with it.



	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
1. My child does not usually yell and scream when things do not go his/her way.	<input type="checkbox"/>				
2. My child never has tantrums.	<input type="checkbox"/>				
3. My child aggravates others.	<input type="checkbox"/>				
4. My child is never aggressive and violent toward others.	<input type="checkbox"/>				
5. My child does not mind when I leave them at home with another adult while I go out.	<input type="checkbox"/>				
6. My child can be stubborn and uncooperative.	<input type="checkbox"/>				
7. I am able to manage my child's behaviour easily at home.	<input type="checkbox"/>				
8. I am able to manage the most challenging and difficult behaviours effectively on my own at home.	<input type="checkbox"/>				
9. My child is happy and content at home most of the time.	<input type="checkbox"/>				
10. My child follows the family routine easily.	<input type="checkbox"/>				
11. My child copes well with disruption to the family routine.	<input type="checkbox"/>				

Some parents say that having a child with an ASC or other disability affects their work and their health. The first questions in this section ask you about this, and then we finish off with some questions about the support and services your child has used.



1. Are you working at all at the moment?

Paid employment Volunteer work Primary home maker (*go to q.5*)

Long-term sick (*go to q.5*) Unemployed / job seeking (*go to q.5*)

Student (*go to q.5*) Retired (*go to q.5*)

ONLY ANSWER THESE QUESTIONS IF YOU ARE CURRENTLY WORKING (IF NOT GO TO Q.5)

2. What is your job/ occupation? _____

3. How many hours a week do you usually work?

30 hours or more Less than 30 hours

4. In the last 3 months have you had to take time off work because of your child's behaviour problems?

No Yes, approximately _____ days in the last three months.

NOW PLEASE GO TO QUESTION 6

ONLY ANSWER THIS QUESTION IF YOU ARE CURRENTLY NOT WORKING

5. In the past 3 months have there been any days when your child's problems have meant that you felt you couldn't take part in your usual activities?

No Yes, approximately _____ days?

6. Do you think that your child's behaviour problems have affected your health?

No (*please go to qu. 8*)
 Yes (*please go to qu. 7*)



7. Have you sought help in the last three months from any service because your child's behaviour problems have affected your health?

No (*please go to qu. 8*)
 Yes, please tell us (on the next page) where you have gone for help in the last three months because your child's behaviour problems have affected your health:

		<i>Approximately how many times in <u>the past three months</u> have you used this service?</i>
<input type="checkbox"/>	GP	
<input type="checkbox"/>	Practice nurse	
<input type="checkbox"/>	Hospital outpatient clinic	
<input type="checkbox"/>	Counsellor	
<input type="checkbox"/>	Alternative therapist	
<input type="checkbox"/>	Self help or Support group	
<input type="checkbox"/>	Website/ Telephone helpline	
<input type="checkbox"/>	Other	

This section is all about the support and services your child has received or used in the past three months.

8. In the past 3 months has your child had any prescriptions for medication?

No Yes. How many? _____

9. In the past 3 months, how many times has your child....? (please tick if you have used this service and insert how many times you have used it)

Visited accident and emergency: _____ times. Stayed overnight in hospital: _____ times

10. Does your child use a short break services?

No Yes, please tell me about how many days a year? _____

12. Please tick which support and services your child has received/ used in the past three months and give detail about how often they have used them.

		<i>If yes, about how many times in the past 3 months?</i>
<input type="checkbox"/>	GP for help with child's behaviour	
<input type="checkbox"/>	GP for other reasons	
<input type="checkbox"/>	Health visitor / specialist health visitor about child's behaviour	
<input type="checkbox"/>	Health visitor / specialist health visitor for other reasons	
<input type="checkbox"/>	Community nurse about child's behaviour	
<input type="checkbox"/>	Community nurse for other reasons	
<input type="checkbox"/>	Hospital outpatient appointment/clinics for child's behaviour	
<input type="checkbox"/>	Hospital outpatient appointment/clinics for other reasons	
<input type="checkbox"/>	Practice nurse	
<input type="checkbox"/>	Alternative therapist	
<input type="checkbox"/>	Social worker	
<input type="checkbox"/>	Key worker	
<input type="checkbox"/>	Home help/home care worker	
<input type="checkbox"/>	Family support worker	

Please tick if you have had any appointments in the past 3 months with any of the following people which have taken place somewhere other than a hospital?

<input type="checkbox"/>	Specialist doctor (not GP)
<input type="checkbox"/>	Family therapist
<input type="checkbox"/>	Child and adolescent mental health team
<input type="checkbox"/>	Speech and language therapist
<input type="checkbox"/>	Occupational therapist

12. What type of school did you child go to last term?

Too young to attend school/ nursery
 (please move to the next section on page 9)

Nursery (not child-care) / pre-school

Mainstream primary school

Special unit in mainstream school

Special school

Secondary school

Other (please describe) _____



13. During this last term how many days a week did your child usually go to nursery/school? _____

14. Did your child have any days off during this last term because of his/her behaviour problems?

No Yes, please tell me about how many times? _____

15. Does your child have a statement of educational needs (SEN statement)?

No Yes

16. Has your child ever been excluded from school?

No Yes, please describe how your child has been excluded:

<input checked="" type="checkbox"/>		<i>Approximately how many days or months?</i>
<input type="checkbox"/>	Permanently excluded	
<input type="checkbox"/>	Formally excluded	
<input type="checkbox"/>	Excluded informally	

Finally, we would like to collect some information about you and your child. We ask these so that we can see who the [name of intervention] Group is helping. First of all there are some questions about your child who you are attending [name of intervention] for to help you with their behaviour.



1. Is your child a boy or a girl? Boy Girl

2. What is their date of birth? ____ / ____ / ____ (dd/mm/yyyy)

3. Does your child have a particular condition or have they had a diagnosis?

No. *Please describe your child's additional needs/ disabilities.*

Yes (*please answer questions a-c*)

a. What is the main diagnosis of your child? _____

b. How long have they had this diagnosis?

Less than six months Six months to one year
 Between one and two years Over two years

c. Does your child have any other disabilities or additional needs?

No Yes (*please describe*) _____

4. Is this your first or only child?

Yes No

5. Do you have any other children with any disabilities or special needs?

Yes, tell us how many: _____ No

The following questions are about you.

6. Are you? (*please tick one box only*)

Married or living as married Separated or divorced
 Single Widowed

7. Please tell us if you have any of this qualifications listed here. These could be qualifications you got at school or after school through further education or work. Tick every box that applies to you. If your UK qualification is not listed, tick the box that contains its nearest equivalent.

- O Levels/CSEs/GCSEs
- NVQ level _____ (*please tell us which level*)
- A/AS Levels
- GNVQ level _____ (*please tell us which level*)
- University degrees and professional qualifications (e.g. teaching, accountancy, nursing)
- Apprenticeship
- City and Guilds Craft
- BTEC First
- BTEC National
- BTEC Advanced Craft
- Other educational qualifications (*please describe*)

8. Which best describes your ethnic group? (*please tick one*)

White

- English/Welsh/Scottish/ Northern Irish/British
- White Irish
- Gypsy or Irish Traveller
- Black or Black British- Caribbean
- White Other
- Other Black/African/Caribbean

Black/African/Caribbean/Black British

- African
- Caribbean
- Black or Black British- Caribbean
- Other Black/African/Caribbean

Mixed/multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Other mixed/multiple ethnic groups

Asian or Asian British

- Indian
- Bangladeshi
- Pakistani
- Chinese
- Other Asian or Asian British

Arab

Other ethnic group

9. What language do you prefer to use?

- English
- Other (including sign language) _____ (*please specify*)

Thank you for completing this questionnaire.



Please complete the consent form on page 11. Then please either return the questionnaire to us in the reply paid envelope provided or bring along to the session next week.

The SPaR Project

Parent Consent Form

The SPaR Project



The Supporting Parents Research Project

Please consider and respond to the following points before signing this consent form. Your signature confirms that you are happy to participate in the study.

Please tick:

- I have read and understood the information provided about what taking part in the SPaR Project involves.
- I am willing to take part in the SPaR Project by completing the SPaR Project's Questionnaire Booklet 3 times over the next 6 months.
- I agree to [service provider] passing a copy of the record of the goals I would like to achieve from attending the [name of intervention] group to the SPaR Project team.
- I understand that my participation is entirely voluntary, and that I am free to withdraw from the research at any time without giving a reason.
- I understand that the information collected from the Questionnaire Booklets, goal records which parents complete will be used to write up a report on the project, as well as articles for journals and newsletters.
- I understand that all the information collected will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written as a result of this research.
- I understand that the information I provide is subject to the Data Protection Act.
- I confirm I would like to participate in this research**

Name: _____ Child's name: _____

Signature: _____ Date: _____ / _____ /2010

Thank you. Once received this form will be detached from the questionnaire and stored separately. A member of the SPaR project team will sign this form in the box below. We will then send you a copy of this form

I confirm, on behalf of the SPaR project team, that we will conduct this research in the way outlined in the project information sheet.

Name of researcher: _____

Signature of researcher: _____ Date: _____ / _____ /2010



SPaR Project Team: Lucy Stuttard, Social Policy Research Unit, York, YO10 5DD. Tel: 01904 321965 / Email: lcs500@york.ac.uk

Thank you for completing this questionnaire



If you would like to discuss the research project further or have any questions, please contact:

Lucy Stuttard, The SPaR Project

Social Policy Research Unit, University of York, York, YO10 5DD

Tel: 01904 321965 / Email: lcs500@york.ac.uk

THE UNIVERSITY *of* York

 **SPRU** | Social Policy Research Unit

The SPaR Project



The Supporting Parents Research Project

Questionnaire Booklet 1: for parents attending [name of intervention]

Thank you very much for taking the time to fill in this booklet.

This booklet is all about your child, their sleep patterns and difficulties, and being a parent of a child with additional needs (such as learning difficulties, autism or physical disabilities). It should take no longer than 20 minutes to fill in.

- Please answer the questions for the child for whom you are seeking help with their sleep.
- If you have more than one child with additional needs and sleep problems, please answer these questions for the child who has the most difficulties.

Once you have filled in the questionnaire please use the reply paid envelope to return it to us.

If you need any help filling in the questionnaire, or have any questions please contact Sue Clarke: 01904 321961, or write to her at: Social Policy Research Unit, University of York, York, YO10 5DD. Email: sec15@york.ac.uk.

Are you coming along to the sessions with anyone else? (please tick)

No

Yes (please tell us who is coming with you)

Child's other parent

Grandparent (to the child)

Someone else (please describe): _____

Why I wanted support from [name of intervention]

By attending the [name of intervention], you are going to cover things you can do at home that may help to manage your child's bedtime routine and sleep behaviour.



Before you begin to make changes at home we would like you to think of up to three sleep goals for your child that are **S**mall, **M**easurable, **A**chievable, **R**elevant, **T**ime Based. In a couple of months we will ask what progress has been made towards these goals, so please try and think of goals that are at least partly achievable in that time.

Some examples of SMART goals are:

Self settles within ten minutes of going to bed 5 out of 7 nights

Night wakenings reduce to 2 out of 7 nights

Sleeps in their own bed 50% of the time.

Please have a think of what things you would like to see change in over the next few months. The degree of change should be set by what you think is realistic and achievable.

My first goal: _____

This is where I am now with this goal:

Very far from my goal 1 2 3 4 5 6 7 8 9 10 *I have achieved this goal*

My second goal: _____

This is where I am now with this goal:

Very far from my goal 1 2 3 4 5 6 7 8 9 10 *I have achieved this goal*

My third goal: _____

This is where I am now with this goal:

Very far from my goal 1 2 3 4 5 6 7 8 9 10 *I have achieved this goal*

Your Child's Sleep Habits

Here are some statements about children's sleep habits and possible difficulties.



We are interested in finding out a bit more about your child whose sleep habits you are hoping to improve. Think about the **past week** when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection or you were on holiday), choose the most recent typical week.

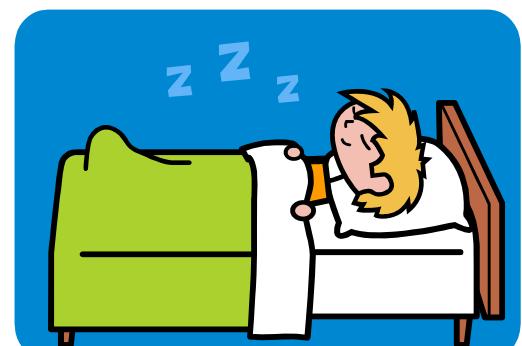
- Tick '**Usually**' if something occurs **5 or more times** in a week;
- Tick '**Sometimes**' if it occurs **2-4 times** in a week;
- Tick '**Rarely**' if something occurs **never or 1 time** during a week.

Bedtime	<i>Usually (5-7 nights/week)</i>	<i>Sometimes (2-4 nights/week)</i>	<i>Rarely (0-1 nights/week)</i>
1. Child goes to bed at the same time at night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Child falls asleep within 20 minutes after going to bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Child falls asleep alone in own bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Child falls asleep in parent's or sibling's bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Child needs parent in the room to fall asleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Child struggles at bedtime (cries, refuses to stay in bed etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Child is afraid of sleeping in the dark	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Child is afraid to sleep alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep behaviour			
9. Child sleeps too little	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Child sleeps the right amount	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Child sleeps about the same amount each day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Child wets the bed at night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Child talks during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Child is restless and moves a lot during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Child sleepwalks during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Child moves to someone else's bed during the night (parent, brother, sister etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Child grinds teeth during sleep (your dentist may have told you this)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Usually (5-7 nights/week)</i>	<i>Sometimes (2-4 nights/week)</i>	<i>Rarely (0-1 nights/week)</i>
18. Child snores loudly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Child seems to stop breathing during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Child snorts and/or gasps during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Child has trouble sleeping away from home (visiting relatives, holidays)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Child awakens during night screaming, sweating, and inconsolable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Child awakens alarmed by a frightening dream	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Waking during the night			
24. Child awakes once during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Child awakes more than once during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Morning waking			
26. Child wakes up by him/herself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Child wakes up in negative mood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Adults or siblings wake up child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Child has difficulty getting out of bed in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Child takes a long time to become alert in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Daytime sleepiness			
31. Child seems tired (during the daytime)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the <u>past week</u>, has your child appeared very sleepy or fallen asleep during the following activities?				
	<i>Not sleepy</i>	<i>Very sleepy</i>	<i>Falls asleep</i>	<i>My child has not done this activity this week</i>
32. Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Riding in car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How long has your child been having problems with their sleep?



Less than 3 months 6-12 months

3 -6 months More than 12 months

These questions are about how people feel about being a parent. Below are things that parents have said about being a parent. For each statement, please tick the box which shows how much you agree or disagree with it.

	Strongly agree	Agree	Slightly agree	Slightly disagree	Disagree	Strongly disagree
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child. I have acquired this understanding	<input type="checkbox"/>					
2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age	<input type="checkbox"/>					
3. I go to bed the same way I wake up in the morning, feeling I have not accomplished much	<input type="checkbox"/>					
4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated	<input type="checkbox"/>					
5. My mother/father was better prepared to be a good mother/father than I am	<input type="checkbox"/>					
6. I would make a fine model for a new mother/father to follow so that she/he could learn to be a good parent	<input type="checkbox"/>					
7. Being a good parent is manageable, and any problems are easily solved	<input type="checkbox"/>					
8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one	<input type="checkbox"/>					
9. Sometimes I feel like I'm not getting anything done as a parent	<input type="checkbox"/>					
10. I meet my own personal expectations in my ability to care for my child	<input type="checkbox"/>					
11. If anyone can find the answer to what is troubling my child, I am the one	<input type="checkbox"/>					
12. My talents and interests are in other areas, not in being a parent	<input type="checkbox"/>					
13. Considering how long I've been a mother/father, I feel thoroughly familiar with this role	<input type="checkbox"/>					
14. If being a mother/father of a child were only more interesting, I would try harder to do a good job as a parent	<input type="checkbox"/>					



Strongly agree	Agree	Slightly agree	Slightly disagree	Disagree	Strongly disagree
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15. I honestly believe that I have all the skills necessary to be a good mother/father to my child

<input type="checkbox"/>					
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

16. Being a parent makes me tense and anxious

<input type="checkbox"/>					
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

The following questions are about yourself and your child. We ask these to find out more about the types of families that are attending [name of intervention]. First, there are some questions about the child for whom you are seeking help with their sleep.

1. Is your child a boy or a girl? Boy Girl

2. What is their date of birth? ____ / ____ / ____ (dd/mm/yyyy)

3. Does your child have a particular condition or have they had a diagnosis?

No. *Please describe your child's additional needs/ disabilities.*

Yes (*please answer questions a-c*)

a. What is the main diagnosis of your child?

b. How long have they had this diagnosis?

Less than six months

Six months to one year

Between one and two years

Over two years

c. Does your child have any other disabilities or additional needs?

No

Yes (*please describe*)

4. Is this your first or only child?

Yes

No

5. Do you have any other children with any disabilities or special needs?

Yes, tell us how many: _____

No

The following questions are about you.

6. Are you? (please tick one box only)

Married or living as married
 Single

Separated or divorced
 Widowed

7. Please tell us if you have any of this qualifications listed here. These could be qualifications you got at school or after school through further education or work. Tick every box that applies to you. If your UK qualification is not listed, tick the box that contains its nearest equivalent.

O Levels/CSEs/GCSEs

NVQ level _____ (please tell us which level)

A/AS Levels

GNVQ level _____ (please tell us which level)

University degrees and professional qualifications (e.g. teaching, accountancy, nursing)

Apprenticeship

City and Guilds Craft

BTEC First

City and Guilds Advanced Craft

BTEC National

Other educational qualifications (please describe) _____

8. Which best describes your ethnic group? (please tick one)

White

English/Welsh/Scottish/ Northern Irish/British
 White Irish
 Gypsy or Irish Traveller
 White Other

Black/African/Caribbean/Black British

African
 Caribbean
 Black or Black British- Caribbean
 Other Black/African/Caribbean

Mixed/multiple ethnic groups

White and Black Caribbean
 White and Black African
 White and Asian
 Other mixed/multiple ethnic groups

Asian or Asian British

Indian
 Bangladeshi
 Pakistani
 Chinese
 Other Asian or Asian British

Arab

Other ethnic group

9. What language do you prefer to use?

English Other (including sign language) _____ (please specify)

Some parents say that having a child with an ASC or other disability affects their work and their health. The first questions in this final section ask you about this, and then we finish off with some questions about the support and services your child has used.

1. Are you working at all at the moment?

Paid employment Volunteer work Primary home maker (*go to q.5*)
 Long-term sick (*go to q.5*) Unemployed / job seeking (*go to q.5*)
 Student (*go to q.5*) Retired (*go to q.5*)

ONLY ANSWER QUESTIONS 2 - 4 IF YOU ARE CURRENTLY WORKING (if not please go to Q.5)

2. What is your job/ occupation? _____**3. How many hours a week are you paid to work?**

30 hours or more Less than 30 hours

4. In the last 3 months have you had to take time off work because of your child's sleep problems?

No Yes, approximately _____ days in the last three months.

NOW PLEASE GO TO QUESTION 6

ONLY ANSWER THIS QUESTION IF YOU ARE NOT WORKING AT THE MOMENT.

5. In the past 3 months have there been any days when your child's problems have meant that you felt you couldn't take part in your usual activities?

No Yes, approximately _____ days?

6. Do you think that your child's sleep problems have affected your health?

No (*please go to qu. 8*) Yes (*please go to qu. 7*)

7. Have you sought help from any service because your child's sleep problems have affected your health?

No (*please go to qu. 8*) Yes. Please use the checklist below to tell us where you've gone for help.

✓

Approximately how many times in the past 3 months have you seen this person/ used this service?

GP
 Practice nurse
 Hospital outpatient clinic
 Counsellor
 Alternative therapist
 Self help or Support group

Website/ Telephone helpline

Other _____

This final section is all about the support and services your child has received or used in the past three months.

8. In the past 3 months has your child had any prescriptions for medication?

No Yes. How many? _____

9. In the past 3 months, how many times has your child....? (please also tell us how many times)

Visited accident and emergency: _____ times. Stayed overnight in hospital: _____ times

10. Does your child use a short break (or respite care) services?

No Yes, please say about how many days a year: _____

11. Please tick all the support and services your child has received/ used in the past three months and give detail about how often they have used them.

<input checked="" type="checkbox"/>		<i>If yes, about how many times in the past 3 months?</i>
<input type="checkbox"/>	GP for help with child's sleep	
<input type="checkbox"/>	GP for other reasons	
<input type="checkbox"/>	Health visitor / specialist health visitor about child's sleep	
<input type="checkbox"/>	Health visitor / specialist health visitor for other reasons	
<input type="checkbox"/>	Community nurse about child's sleep	
<input type="checkbox"/>	Community nurse for other reasons	
<input type="checkbox"/>	Hospital outpatient appointment/clinics for child's sleep	
<input type="checkbox"/>	Hospital outpatient appointment/clinics for other reasons	
<input type="checkbox"/>	Practice nurse	
<input type="checkbox"/>	Alternative therapist	
<input type="checkbox"/>	Social worker	
<input type="checkbox"/>	Key worker	
<input type="checkbox"/>	Home help/home care worker	
<input type="checkbox"/>	Family support worker	

In the past 3 months, has your child has had any appointments with any of the following people which have taken place somewhere other than a hospital? How many times your child has seen them.

About how many appointments?

<input type="checkbox"/>	Specialist doctor (not GP)	
<input type="checkbox"/>	Family therapist	
<input type="checkbox"/>	Child and adolescent mental health team	
<input type="checkbox"/>	Speech and language therapist	
<input type="checkbox"/>	Occupational therapist	

12. What type of school did you child go to last term?

Too young to attend school/ nursery (*you do not need to answer any more questions*)

Nursery (not child-care) / pre-school

Mainstream primary school

Special unit in mainstream school

Special school

Secondary school

Other (*please describe*) _____

13. During the last term how many days a week did your child usually go to nursery/school?

14. During the last term, did your child have any days off nursery/school because of his/her sleep problems?

No Yes, *please say about how many times?* _____

15. Does your child have a statement of educational needs (SEN statement)?

No Yes

16. Has your child ever been excluded from school?

No Yes, *please use the checklist below to describe how your child has been excluded:*

<input checked="" type="checkbox"/>		<i>Approximately how many days or months?</i>
<input type="checkbox"/>	Permanently excluded	
<input type="checkbox"/>	Formally excluded	
<input type="checkbox"/>	Excluded informally	

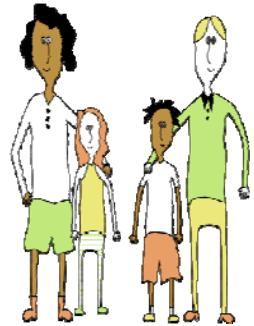
Thank you very much for completing this questionnaire

Please turn over and complete the contact details sheet and consent form, and then return the questionnaire to us in the reply paid envelope provided.

Taking part in the SPaR project

As part of the project we will would like to send you two more questionnaires to see how you feel after receiving support from [name of intervention]. For this we need your contact details. Can you please complete these below. Once received, these will be detached from the rest of the booklet and stored separately.

The SPaR Project



The Supporting Parents Research Project

Do you have the main responsibility for the day to day care of your child?

Yes No Responsibility equally shared with partner

What is your relationship to the child? (mother, father, grandparent, etc)

Address:

Telephone (home):

(mobile/text):

Email (optional):

The best times to contact me are:

(please tick)

<input type="checkbox"/> weekday mornings	<input type="checkbox"/> Saturday daytime
<input type="checkbox"/> weekday afternoons	<input type="checkbox"/> Saturday evenings
<input type="checkbox"/> weekday evenings: 6pm -7.30pm	<input type="checkbox"/> Sunday daytime
<input type="checkbox"/> weekday evenings: 7.30pm - 9pm	<input type="checkbox"/> Sunday evenings

PLEASE TURN OVER



The SPaR Project

Parent Consent Form

This consent form shows that you understand what taking part in this research involves, and that you are happy to take part.



Please consider and respond to the following points before signing this consent form. Your signature confirms that you are happy to participate in the study.

Please tick:

- I have read and understood the information provided about what taking part in the SPaR Project involves.
- I am willing to take part in the SPaR Project by completing the SPaR Project's Questionnaire Booklet 3 times over the next 5 months.
- I understand that my participation is entirely voluntary, and that I am free to withdraw from the research at any time without giving a reason.
- I understand that the information collected from the Questionnaire Booklets which parents complete will be used to write up a report on the project, as well as articles for journals and newsletters.
- I understand that all the information collected will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written as a result of this research.
- I understand that the information I provide is subject to the Data Protection Act.
- I confirm I would like to participate in this research**

Name: _____ Child's name: _____

Signature: _____ Date: _____ / _____ /2010

Thank you. Once received this form will be detached from the questionnaire and stored separately. A member of the SPaR project team will sign this form in the box below. We will then send you a copy of this form

I confirm, on behalf of the SPaR project team, that we will conduct this research in the way outlined in the project information sheet.

Name of researcher: _____

Signature of researcher: _____ Date: _____ / _____ /2010



To contact the SPaR Project Team: Sue Clarke, Social Policy Research Unit, University of York, York, YO10 5DD. Tel: 01904 321961 / Email: sec15@york.ac.uk



E-mail:

Date:

Dear Parent

[Name of intervention] is taking part in a national research project (The SPaR project). This project is studying if support services, like [name of intervention], help parents with a child with an ASC or other disabilities with their child's behaviour/sleep. Parents' views and experiences are the main way we will be finding out if such services are helpful.

[Name of lead contact] is sending this letter and project information sheet to you because you are about to receive support from [name of intervention]. The project information sheet explains more about why we are doing this research, what taking part involves and how you can take part.

Please be assured that you do not have to take part in this research just because you are receiving support from [name of intervention]. Taking part in this research is entirely up to you. Your decision about taking part in this research will not affect the services and support you and your child receives, including [name of intervention].

We hope you find the information leaflet interesting. If you have any questions about taking part please do get in touch with us, we would be happy to answer any questions you have. It's also fine to chat to [name of lead contact] about taking part.

With best wishes

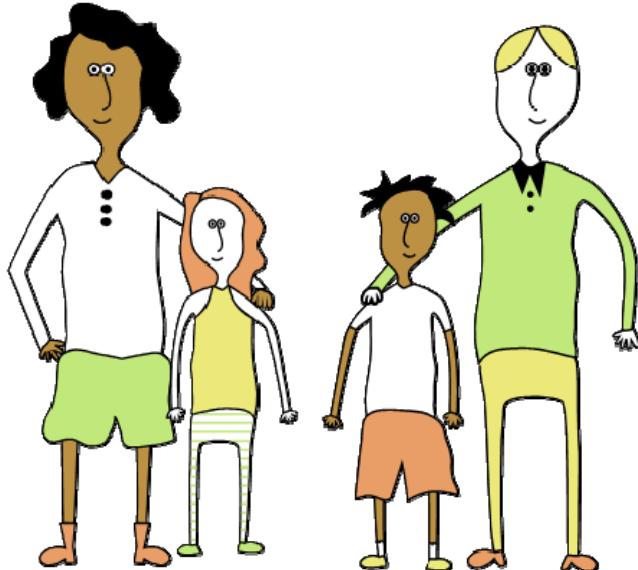
Lucy Stuttard
(The Research Team)

Sue Clarke

Bryony Beresford

Encs.

The SPaR Project



The Supporting Parents Research Project

Information for parents about the SPaR project

[Name of intervention] is taking part in a research project which is studying services which help parents with their child's sleep or behaviour.

This project is called the **SPaR** project.

This leaflet tells you more about this research and how parents can take part.

About the SPaR project

- Sleep/behaviour problems are common among disabled children or children with an autism spectrum condition (ASC).
- However, few of these families get help with their child's sleep/behaviour.
- A government body (the Department for Children, Schools and Families) has asked us to find out what parents think of the services which help them manage their child's sleep/behaviour.
- We are researching different 'support services' across England to see which work best for families and offer the best value.
- We are asking parents who have been offered one of these 'support services' to take part in this research.
- [Name of intervention], run through [service provider], is one of the 'support services' that we are researching.
- Taking part in the research involves completing some simple questionnaires on three occasions.



An invitation to take part in this research project

- You are being invited to take part in this research because you are just about to start receiving support from [name of intervention].
- Taking part will involve completing some short questionnaires three times over the next six months. Filling in the questionnaires will take no longer than 20 minutes.
- You do not have to take part in this research just because you are receiving support from [name of intervention].
- **If you decide not to take part in this research, it will not affect any of the help or support you receive for your family.**
- Please read all the information in this booklet carefully, before deciding whether or not you would like to participate.

The purpose of the research

This research is trying to find out if 'support services' do help parents with a child with an ASC or other disability manage their child's sleep/behaviour. This research is being done because the government wants to know how to best help these families.



Why have I been invited to take part?

You have been invited to take part because you are just about to start receiving support from [name of intervention]. All parents attending this group this year will be invited to take part in this research.

What would taking part involve?

Taking part will involve completing a short questionnaire booklet on three occasions over the next five months. The questions are about your child and their sleep/behaviour, being a parent, the services you and your child use and some general questions about you and your child (e.g. diagnosis). You will also be asked to set some goals that you would like to achieve from receiving support from [name of intervention].

Some parents will also be invited to take part in an informal interview with a member of the research team about their experiences of receiving support from [name of intervention]. These interviews will take place in about 3-6 months' time. Parents chosen to take part in an interview will receive a separate letter about this.

Do I have to take part?

No. You decide whether or not to take part. Your decision will not affect any of the services your child and family receives, including the [name of intervention] group.

How do I become involved?

If you would like to take part, please complete the enclosed questionnaire booklet. We will then send you another questionnaire around the time you finish receiving support from [name of intervention] and one about three months later. We can help with filling in the questionnaires – please let us know if you would like help.



Will my taking part be kept confidential?

The information collected during this research project will be treated with the strictest confidence and no-one taking part in the project will be identifiable in the project report or any other publication. You can tell whoever you want about taking part in the project, but we will not tell anyone that you are taking part in the project.

What are the possible risks and benefits of taking part?

The purpose of this research project is to increase understanding about what types of behaviour support services work best for families with a child with an ASC or other disabilities. There are no personal benefits to parents who take part in the research. However, the findings from the research will help to inform the type of behaviour support services available for families with a disabled child.

What happens when the research is completed?

We will send you a summary of the findings of the research and you will also be able to request a copy of the full project report. The summary and full report will be posted on our project website and anyone will be able to read and/or download them.

The research team

The research project is based in the Social Policy Research Unit at the University of York. Lucy Stuttard, Sue Clarke and Bryony Beresford are the three researchers working on this project.

Any questions?

If you would like to discuss the research project further or have any questions, please contact: Lucy Stuttard, The SPaR Project, Social Policy Research Unit, University of York, York. YO10 5DD Tel: 01904 321965/ email: lcs500@york.ac.uk.



Annex B

Qualitative Research Tools – Parents

Insert ref here

Insert name and address here

E-mail: sec15@york.ac.uk

Date

Dear Parent

We are writing to you because you attended [name of intervention]. You may remember that [name of intervention] is taking part in a national research project (The SPaR project) being carried out at the University of York. This project is studying if support services, like [name of intervention], help parents with a child with an autistic spectrum condition or other disabilities, who have difficulties with their sleep or behaviour. Several of you have completed our questionnaires and we are very grateful for this.

Another part of the SPaR project is to find out about parents' experiences of going along to support groups like [name of intervention]. This letter is to invite you to a focus group meeting for parents who attended [name of intervention] in the last year. All parents who attended [name of intervention] are very welcome to come to this meeting, not just those who completed our questionnaires.

The meeting will take place at **[venue]** on **[date]** from **[time]**. Tea/coffee will be provided from 11.15am for a prompt start at 11.30am. We will then provide lunch.

We expect there will be around 10 other parents at the meeting. We will be asking you about what it was like attending [name of intervention] and what you found most useful, and least useful, in helping you as a parent. The enclosed information leaflet tells you more about the focus group.

Please be assured that you are under no obligation to take part in this focus group. Your decision or not to take part will not affect the services and support you and your child receives. If you have any questions about taking part please do get in touch with us, or if you prefer, with [intervention lead facilitator(s)].

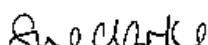
If you would like to attend our focus group meeting, please complete the attached form and return it to us using the reply paid envelope. We will back in touch before the focus group to confirm arrangements.

Thank you for your interest in this research project.

With best wishes



Lucy Stuttard
(The Research Team)



Sue Clarke



Bryony Beresford

Taking part in a focus group for the SPaR project



Please complete this form if you would like to take part in a focus group about your experiences of [name of intervention] at **[venue]** on **[date]** from **[time]**.

Name: _____

Please tick to indicate which group you attended:

Group 1 Group 2

Group 3 Group 4

Address: _____

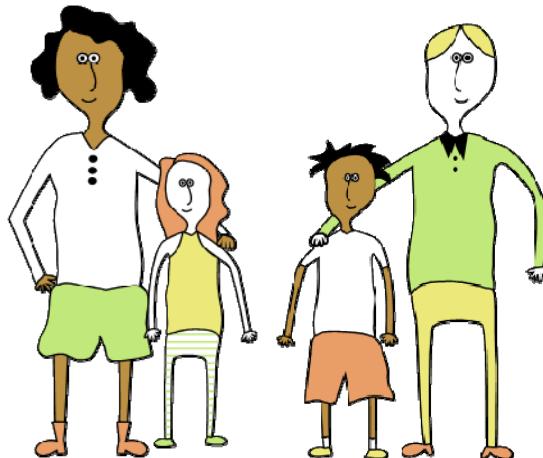
Phone(s): _____

If you have any questions about the SPaR project, please contact:
Sue Clarke, The SPaR Project, Social Policy Research Unit, The University of York, York.
YO10 5DD

Tel: 01904 321961/ email: sec15@york.ac.uk.

Please return the form to the SPaR project team using the reply paid envelope provided. Thank you.

The SPaR Project



The Supporting Parents Research Project

Information for parents about taking part in a focus group about going along to [NAME OF INTERVENTION].

- This leaflet gives parents more information about why the SPaR project is inviting you to take part in a focus group.
- Please read the leaflet carefully before deciding if you want to take part in the focus group.
- Please be assured that you do not have to take part in this aspect of the SPaR project. Taking part is entirely your decision. Whatever you decide will not affect the services and support you and your child receives.

*Please contact Sue Clarke if you have any questions about taking part :
The SPaR Project, Social Policy Research Unit, University of York, York.
YO10 5DD Tel: 01904 321961/email: sec15@york.ac.uk.*

Background

So far in the **SPaR** project, parents have been filling in our Questionnaire Booklet. The Questionnaire Booklet contains questionnaires about their child, their experiences as a parent and the help they have been receiving.

We are very grateful to all the parents who have taken the time to complete the **SPaR** project Questionnaire Booklets.

Why the focus groups are taking place

We would like to add to the information collected in the Questionnaire Booklets by hearing directly from parents about their experiences of receiving the behaviour support services we are investigating, including [NAME OF INTERVENTION].

Why we are inviting you to take part in a focus group

We are inviting parents who have attended [NAME OF INTERVENTION] to attend a focus group. Some of the other parents at the focus group will be those you met when you attended [NAME OF INTERVENTION].



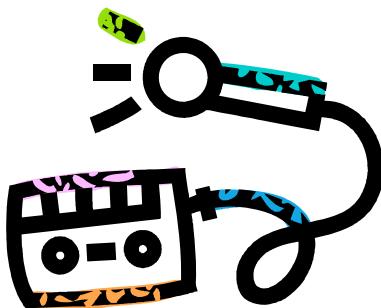
What will taking part in a focus group involve?

A focus group is an informal group discussion. The focus group will last around 1 to 1½ hours. Members of the **SPaR** project team will run the focus group. There will be around ten other parents at the focus group, some of them will have been to the [NAME OF INTERVENTION] group you went along to.

In the group we would like to discuss: getting along to [NAME OF INTERVENTION], what you enjoyed and found helpful about [NAME OF INTERVENTION], and what you did not enjoy or find helpful. We are also interested to hear how [NAME OF INTERVENTION] helped you change the way you manage your child's behaviour and whether it has been easy to carry on doing the things you learnt about from [NAME OF INTERVENTION].

I am not completing the questionnaires for the SPaR Project – should I still come along?

We would like all parents who attended [NAME OF INTERVENTION] to come along, whether or not they completed the **SPaR** project questionnaire booklets.



Recording the focus group

We would like to record the focus group. This means we have a complete record of the discussion. We like to record focus groups because it's very difficult to keep accurate notes in these meetings.

Do I have to take part?

No. You decide whether or not to take part. Your decision will not affect any of the services your child and family receive.

How do I let the SPaR Project team know I am happy to attend?

If you would like to take part in the focus group, please complete the form attached to the letter which came with this information leaflet.

Please send your completed form to the **SPaR** project team. We will contact you before the focus group to make sure you have up-to-date details of the time, venue etc.

Will the focus group be kept confidential?

Yes. All the information collected during the **SPaR** project is being treated with the strictest confidence and no-one taking part in the project will be identifiable in the project report or any other publication.

Reports of the findings from the study may include short quotes from parents about their views and experiences. However, the quotes will be anonymous.

What are the possible risks and benefits of taking part an interview?

The overall purpose of the **SPaR** project is to increase understanding about what types of sleep and behaviour support services work best for families with a child with autistic spectrum conditions or other disabilities. There are no personal benefits to parents who take part in a focus group interview. However, we find parents enjoy talking to other parents and researchers about their views and experiences.

What happens when the **SPaR project is completed?**

We will send you a summary of the findings of the research and you will also be able to request a copy of the full project report. The summary and full report will be posted on our project website and anyone will be able to read and/or download them.

The research team

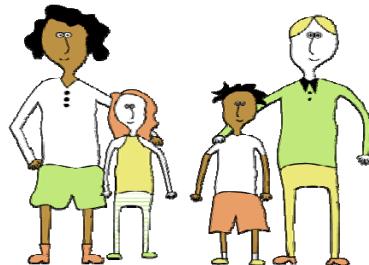
The research project is based in the Social Policy Research Unit at the University of York. Lucy Stuttard, Sue Clarke and Bryony Beresford are the three researchers working on this project.

Any questions?

If you would like to discuss the research project further or have any questions, please contact:

Lucy Stuttard, The **SPaR** Project, Social Policy Research Unit, University of York, York. YO10 5DD. Tel: 01904 321965 / Email: lcs500@york.ac.uk.

The **SPaR Project**



The Supporting Parents Research Project

The SPaR Project

Parent Consent Form



Please consider and respond to the following points before signing this consent form. Your signature confirms that you are happy to participate in a focus group for the study. After the focus group we will send you a copy of this form.

Please tick:

- I have read and understood the information provided about what taking part in a focus group for the **SPaR** Project involves.
- I am willing to take part in a focus group.
- I understand that my participation is entirely voluntary, and that I am free to withdraw from the focus group at any time without giving a reason.
- I understand that the information collected from the focus group with parents will form part of the report on the **SPaR** project, as well as being used in articles for journals and newsletters.
- I understand that all the information collected will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written as a result of this research.
- I understand that, with my permission, the interview will be audio-recorded.
- I understand that the information I provide is subject to the Data Protection Act.
- I confirm I would like to take part in a focus group interview with the **SPaR** project team.**

Signature: _____

Date: ____ / ____ /2010

Name: _____

I confirm, on behalf of the **SPaR project team, that we will conduct this research in the way outlined in the project information sheet.**

Signature of researcher: _____

Date: ____ / ____ /2010

Name: _____

To contact us: Lucy Stuttard, The **SPaR** Project, Social Policy Research Unit, University of York, York. YO10 5DD. Tel: 01904 321965/ email: lcs500@york.ac.uk.

E-mail:

Tel:

Dear Parent

Invitation to talk to us about your experiences

Over the past few months you have been taking part in the SPaR project which is studying how well support services, like [name of intervention], is helping parents with a disabled child who has difficulties with [behaviour/sleep]. We would like to thank you very much for taking part in this research project.

So far you have completed some short questionnaires for us. We would now like to invite you to take part in a short telephone interview with a member of the research team. We are interviewing parents who have received support with their child's behaviour because we think it is important that we hear from parents about their experiences of this.

Please be assured that you do not have to take part in an interview. Your decision or not to take part will not affect the services and support you and your child receives.

An information leaflet about taking part in an interview is enclosed. We hope you find the information leaflet interesting. If you have any questions about taking part please do get in touch with us.

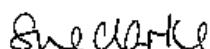
We will telephone you in the next week or so to see if you are happy to take part in an interview and, if so, arrange the interview. We imagine the interview would last around 30-40 minutes.

Once again, thank you for your interest and participation in this research, it is much appreciated.

Yours sincerely



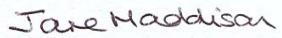
Lucy Stuttard
(The Research Team)



Sue Clarke



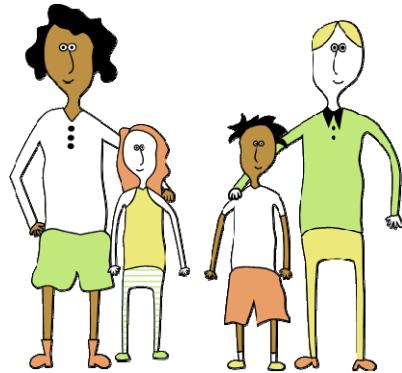
Bryony Beresford



Jane Maddison

Encs.

The SPaR Project



The Supporting Parents Research Project

Additional information for parents about taking part in an interview for the SPaR project

- This leaflet gives parents more information about why the SPaR project is inviting you to take part in an interview.
- Please read the leaflet carefully before deciding if you want to take part in an interview.
- Please be assured that you do not have to take part in this part of the SPaR project. Taking part is entirely your decision. Your decision about taking part in an interview will not affect the services and support you and your child receives.

Please contact Lucy Stuttard if you have any questions about taking part in an interview:

*The SPaR Project, Social Policy Research Unit, University of York, York, YO10 5DD.
Tel: 01904 321965 / Email: lcs500@york.ac.uk*

Background

So far in the **SPaR** project, parents have been filling in our Research Booklet. The Research Booklet contains questionnaires about their child, their experiences as a parent and the help they have been receiving.

We are very grateful for all the parents who have taken the time to complete the **SPaR** project Research Booklets.

Why the interviews are taking place

We would like to add to the information collected in the Research Booklets by hearing directly from parents about their experiences of attending/receiving the sleep and behaviour support services we are investigating, including [name of intervention].

Why we are inviting you to take part in an interview

We are not interviewing all the parents who have completed the Research Booklets. Instead, for each sleep or behaviour support service, we are inviting a small number of parents to take part in an interview.

Using the answers given in the Research Booklets, we are selecting parents who seemed to have found [name of intervention] very helpful, and some parents who may not have found it so helpful.



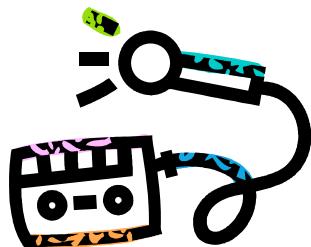
What will taking part in an interview involve?

We are interviewing parents by phone. The interview will last around 30-40 minutes and take place at a date and time convenient to you. A member of the **SPaR** project team will carry out the interview.

Before the interview, we will send you a list of the types of questions we will be asking you. These will include how [name of intervention] helped you change the way you manage your child's behaviour and whether it has been easy to carry on doing the things you learnt about from [name of intervention]. We will also ask you what you enjoyed most and least

about going along to [name of intervention]; how the support you received from [name of intervention] differed from any support you may have received in the past; and any suggestions you may have as to how [name of intervention] could be improved.

Recording the interviews



We find recording interviews means we have a complete record of the interview. However, you can choose not to be recorded, in which case we will make notes whilst we talk to you.

Do I have to take part?

No. You decide whether or not to take part. Your decision will not affect any of the services your child and family receives, including [name of service].

Will my interview be kept confidential?

Yes. All the information collected during the **SPaR** project is being treated with the strictest confidence and no-one taking part in the project will be identifiable in the project report or any other publication.

Reports of the findings from the study may include short quotes from parents about their views and experiences. However, your name will NOT be mentioned to others or published in the reports of our work.

What are the possible risks and benefits of taking part an interview?

The overall purpose of the **SPaR** project is to increase understanding about what types of sleep and behaviour support services work best for families with a disabled child. There are no personal benefits to parents who take part in an interview. However, we find parents enjoy talking to a researcher about their views and experiences.

What happens when the SPaR project is completed?

We will send you a summary of the findings of the research and you will also be able to request a copy of the full project report. The summary and full report will be posted on our project website and anyone will be able to read and/or download them.

The research team

The research project is based in the Social Policy Research Unit at the University of York. Lucy Stuttard, Sue Clarke, Jane Maddison and Bryony Beresford are the four researchers working on this project.

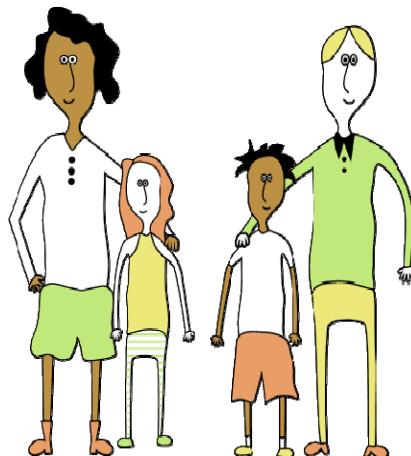
Any questions?

If you would like to discuss the research project further or have any questions, please contact:

Lucy Stuttard
The SPaR Project
Social Policy Research Unit
University of York
York
YO10 5DD.

Tel: 01904 321965 / Email: lcs500@york.ac.uk

The SPaR Project



The Supporting Parents Research Project



The SPaR Project

Parent Consent Form: Interview phase

Please consider and respond to the following points before signing this consent form. Your signature confirms that you are happy to participate in the study. After the interview, we will send you a copy of this form.

Please tick:

- I have read and understood the information provided about what taking part in an interview for the SPaR Project involves.
- I am willing to take part in an interview.
- I understand that my participation is entirely voluntary, and that I am free to withdraw from the interview at any time without giving a reason.
- I understand that the information collected from the interviews with parents will form part of the report on the SPaR project, as well as being used in articles for journals and newsletters.
- I understand that all the information collected will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written as a result of this research.
- I understand that, with my permission, the interview will be audio-recorded.
- I understand that the information I provide is subject to the Data Protection Act.
- I confirm I would like to take part in an interview with a member of the SPaR project team.**

Signature: _____

Date: ___ / ___ / 2010

Name: _____

I confirm, on behalf of the SPaR project team, that we will conduct this research in the way outlined in the project information sheet.

Signature of researcher: _____

Date: ___ / ___ / 2010

Name: _____

To contact us: Lucy Stuttard, The SPaR Project, Social Policy Research Unit, University of York, York, YO10 5DD.
Tel: 01904 321965/Email: lcs500@york.ac.uk

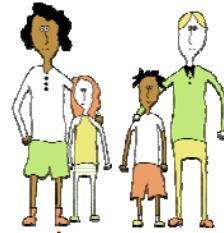
Parent interviews

This is a list of the types of questions we will be asking parents in interviews:

- What did you enjoy most and least about going along to [name of intervention]?
- Did [name of intervention] help you change the way you manage your child's behaviour?
- What helped or got in the way of achieving the goals you had for changing your child's behaviour?
- Has it been easy to carry on doing the things you learnt about from [name of intervention]?
- Since [name of intervention] finished, have you found you have applied what you learnt to other problems/difficulties you have with parenting your child?
- Did [name of intervention] differ from any support you may have received in the past to help with your child's behaviour?
- What were the facilitators/trainers like?
- For you, what were the benefits and drawbacks of receiving this support in a group setting?
- If you attended with anyone else (i.e. your child's other parent or grandparent), how helpful was this?
- Would you like to do the [name of intervention] programme again some time in the future?
- Do you have any suggestions as to how [name of intervention] could be improved?

We imagine the interview will last around 30-40 minutes. There is no need to prepare in advance for this interview. We are interested in what you think, so there are no right or wrong answers. We will not tell [name of intervention] what you said, and we will not use your name in any report of this work.

The SPaR Project

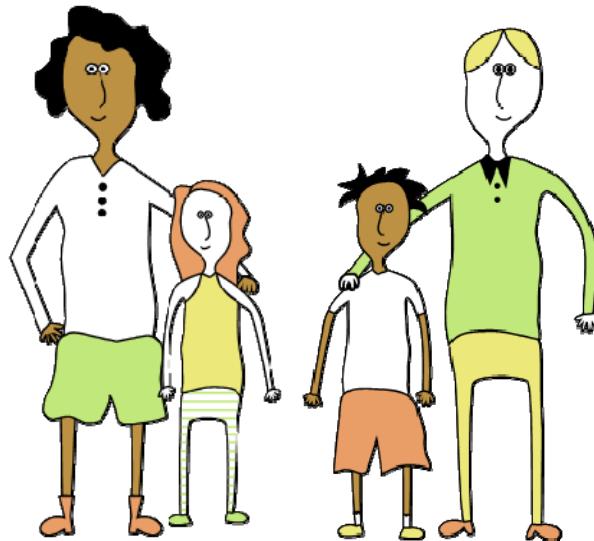


The Supporting Parents Research Project

Annex C

Qualitative Research Tools – Practitioners

The SPaR Project



The Supporting Parents Research Project

Information for professionals about taking part in the SPaR project

The **SPaR** project is studying the effectiveness of interventions to help parents with a disabled child to manage their child's sleep or behaviour difficulty.

An important part of this research is to explore and describe the experiences of the professionals who deliver such interventions.

To achieve this, the **SPaR** project team would like to interview some of the professionals involved in delivering the interventions which have been investigated by the project. This information leaflet explains a bit more about what taking part in an interview would involve.

Our contact details

If you have any questions about taking part in an interview or about the project more generally please contact: *Lucy Stuttard. The SPaR Project, Social Policy Research Unit, University of York, York. YO10 5DD*
Tel: 01904 321965/email: lcs500@york.ac.uk.

Background

So far in the **SPaR** project, parents have been filling in our Research Booklet. The Research Booklet contains measures of child sleep/ behaviour, their experiences as a parent, and the help they have been receiving. Some parents have also taken part in a focus group or have been interviewed by the research team.

Why the interviews are taking place and why we are inviting you to participate

We would like to add to this information by hearing from the professionals who delivering these interventions. This is why we are inviting you to take part in an interview.

What will taking part in an interview involve?

The interview will last between 30-60 minutes. A member of the **SPaR** project team will carry out the interview. You can choose to be interviewed over the phone or we can visit you. The interview would take place at a date and time convenient to you.

You will be asked about: reasons for choosing/developing the intervention used, views on parents' experiences of accessing the intervention, experiences of delivering the intervention, perceived effectiveness of the intervention and the factors which support or interfere with its effectiveness. We would also like to hear your views on the ways in which the intervention, in terms of its content or mode of delivery, could be improved.

Recording the interviews

We find recording interviews means we have a complete record of the interview. However, you can choose not to be recorded, in which case we will make notes whilst we talk to you.

Do I have to take part?

No. Taking part in an interview is entirely voluntary..

Will my interview be kept confidential?

Yes. All the information collected during the **SPaR** project is being treated with the strictest confidence and no-one taking part in the project will be identifiable in the project report or any other publication.

What are the possible risks and benefits of taking part an interview?

The overall purpose of the **SPaR** project is to increase understanding about what types of sleep and behaviour support services work best for families with a disabled child. There are no personal benefits to professionals who take part in an interview.

What happens when the **SPaR project is completed?**

We will be sending you a summary of the findings of the research and you will also be able to request a copy of the full project report. You will also receive a report specific to the service you are involved in delivering. The overall summary and full report will be posted on our project website and anyone will be able to read and/or download them.

How do I let the **SPaR Project team know I am happy to be interviewed?**

If you think you would be happy to be interviewed please let us know by replying to the email that this information leaflet was attached to and we will then arrange a convenient time for the interview to take place.

Insert ref here

Insert name and address here

E-mail: @york.ac.uk

Date

Dear [name]

Thank you very much for agreeing to be interviewed about **[name of intervention]** for the **SPaR** project, it is much appreciated.

As we discussed over the telephone, the interview will take place on the phone at **[time]** on **[date]**. We expect the interview will last around one hour.

I am enclosing a list of the types of questions we will be asking professionals in interviews so you know what to expect. However, please do not think you need to prepare for the interview.

I am also enclosing a copy of the consent form, which we need you to complete and return to us for our records, to show that you were informed about the study and were happy to take part.

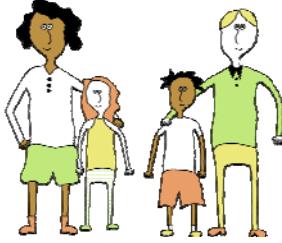
If you have any questions or queries, or need to get in touch with me, please phone [tel no].

I look forward to talking with you soon.

Best wishes

SPaR Project Team

The SPar Project



The Supporting Parents Research Project

INTERVIEWS WITH PROFESSIONALS

Overview of questions

Main desired outcome(s) for parents and children of the intervention.

Views on extent to which the intervention achieves the desired outcomes.

Views on aspects of the intervention which makes it effective.

Views on other factors perceived to affect effectiveness.

Experiences of delivering the intervention, including delivering to ethnic minority groups

Views on what gets in the way of positive outcomes being maintained once the intervention is finished.

Views on impact of the intervention on longer term outcomes.

Views on the general state of support (across the country) available to parents of disabled children regarding managing their child's sleep and/or behaviour.

In addition, professionals who lead/oversee the intervention will be asked about the rationale behind their choice of intervention, take-up/referral, and retention/'drop-out' issues.

The SPaR Project: Consent form for professionals taking part in an interview

Please consider and respond to the following points before signing this consent form. Your signature confirms that you are happy to participate in the study. We will send you a copy of this form.



For each statement, please put your initials in the box to indicate you agree with it.

- I read and understood the information provided about what taking part in an interview for the SPaR Project involved.
- I was willing to take part in an interview.
- I understand that my participation is entirely voluntary, and that I am free to withdraw from the SPaR Project at any time.
- I understand that the information collected from the interviews with professionals will form part of the report on the SPaR project, as well as being used in articles for journals and newsletters.
- I understand that all the information collected will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written as a result of this research.
- I understand that, with my permission, the interview was audio-recorded.
- I understand that the information I provided is subject to the Data Protection Act.

I confirm I was happy to take part in the SPaR project by being interviewed by member of the SPaR Project research team.

Signature: _____

Date: __ / __ / 2010

Name: _____

I confirm, on behalf of the SPaR project team, that the research was conducted in the way outlined in the project information sheet.

Signature of researcher: _____

Date: __ / __ / 2010

Name: _____

To contact us: Lucy Stuttard, The SPaR Project, Social Policy Research Unit, University of York, York. YO10 5DD. Tel: 01904 321965/ email: lcs500@york.ac.uk.

THE UNIVERSITY *of York*

