Priorities and Perceptions of Disabled Children and Young People and Their Parents Regarding Outcomes from Support Services

APPENDICES

DH 2147

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Contents

APPENDIX ONE

Samples of Information Sheets and Consent Forms
Used in Research Phase

(Note: different versions were used according to
condition group and recruitment source)

'WHAT MATTERS?'

Information leaflet for Parents and guardians

The *'What Matters?'* research project

About the research
Professionals who provide services for disabled children and their families want to get a better picture of the sorts of help families really want.   That is why the Department of Health have asked us to carry out the *'What Matters?'* research project. We will use what disabled children/young people and their parents tell us to build up this picture. We will write a report on the findings of the research and make sure it is distributed widely to practitioners and people who work in government departments.   We will also write a report for the families who take part in the research project.

The research project is based in the Social Policy Research Unit at the University of York. There are four of us working on the project. Our names are: Parvaneh Rabiee, Bryony Beresford, Robina Shah and Tricia Sloper.

Who is taking part?
Families from different parts of England are being invited to take part in the research, including families living in Airedale and Bradford. We are asking parents and their disabled child (if aged between 6 and 18 years) to take part in the research. In some families, both a parent and child will want to take part. In others, it might just be a parent or a child.   We do not want to leave anyone out of the project because they have learning difficulties, or because they do not use speech to communicate, or because their first language is not English. We will try our best to find ways to include them in the project.

What the research project involves
If you and/or your child want to take part in the *'What Matters?'* research project one of us will visit you at home. We find it works best if we spend time separately with a parent and their child. In order to do this we might need to make two visits. We are also hoping to arrange one or two group meetings in your area. There will be separate meetings for parents and for children/young people. You and/or your child might like to come along to these meetings.

It may be your child would want someone with them when we visit – that's fine.   Sometimes we will need another person to help us understand what a child or young people wants to tell us. They can choose who this person is.

We find it helpful to tape record group discussions and interviews, but we would not do this if you would prefer us not to.

Covering costs
We will cover any childcare and transport costs you and/or your child have through taking part in the research.

Confidentiality

The information collected during the research project will be treated with 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 disclose to anyone that you and/or your child are taking part in the project.

Deciding about taking part

You and/or your child do not have to take part in this research: it is entirely up to you and your child. You and/or your child can also withdraw from the project at any time without giving a reason. Whether or not you take part will not affect any of the services you or your child receives.

If you and/or your child are happy for a member of the research team to contact you about joining the project please complete the enclosed yellow form. This can be sent to us using the envelope provided. We will then contact you and will be very pleased to answer any other questions you may have about the project. If you agree, we will also arrange a convenient time to visit.

Any questions?

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

Parvaneh Rabiee
Social Policy Research Unit
University of York
York YO1 5DD
Telephone: 01904-433608
Email pr15@york.ac.uk

The 'What Matters?' Project
CONSENT FORM FOR PARENTS

This form is to make sure that we have explained everything that is involved in the research project to your satisfaction, and for you to state whether or not you agree to take part.

Have you read the information sheet about the 'What Matters?' Project and do you feel you understand what taking part in the project involves?

Yes/No

Have you talked to one of the project workers about the project?

Yes/No

Do you know that you are free to withdraw from the study at any time, and without giving a reason? **Yes/No**

Do you know that all the information from the research will be kept strictly private and confidential? **Yes/No**

Do you agree that the information from the research can be published if your identity is kept secret? **Yes/No**

Would you like to take part in the 'What Matters?' project?

Yes/No

Consent for your child to take part

If your child has learning difficulties or is under 16 and wants to take part we also require your consent for this.

Do you understand that your child is free to withdraw from the study at any time, without giving a reason and without affecting any service he/she is using?

Yes/No

Do you know that all the information about your child from the research will be kept strictly confidential? **Yes/No**

Do you agree that information from the research can be published if his/her identity is kept secret?

Yes/No

Are you happy for your child to take part in the 'What Matters?' project?
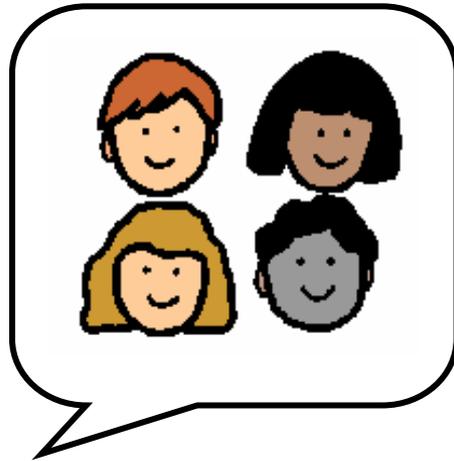
Yes/No

Signed………………………………….   date……………...

Name…………………………………………

'WHAT MATTERS?'

Information leaflet for children

and young people

The 'What Matters?' Research Project

Can you help?
Hello! Our names are Parvaneh, Bryony, Tricia and Robina.

We are talking and listening to children and young people about what matters to them.

We would like to visit you and find out what you like to do. What makes you happy? What makes you sad? What's exciting, what's boring? What stops you doing what you like to do?

What you tell us is important. The people who help disabled children and their families want to improve the support and help they give.

You can choose
Is it OK to visit you? You can say Yes or No. It is OK to say NO.

If you would like to see us, you can choose who is there with you while we talk: on your own, with your mum, dad, brother, sister, a friend or a teacher.

If you have any questions you or your parent/ guardian can ring us or email us or write to us on the number and address below.

Parvaneh Rabiee

'What Matters' Project

Social Policy Research Unit

University of York

Heslington

York YO10 5DD

Telephone: 01904 433608   E-Mail:pr15@york.ac.uk

| Parvaneh | Bryony | Tricia |

'WHAT MATTERS?'

Information leaflet for children
and young people

The *'What Matters?'* Research Project

What's this all about?

The '*What Matters?*' research project is about finding out from disabled children and young people and their families what matters to them. It's about finding out what you want to do – now and in the future. And it's about working out how services can help achieve these things.

The '*What Matters?*' research project is working with disabled children and young people and their parents or guardians in a number of different places in England, including Bradford and Airedale.

The *'What Matters?'* research project is a chance for you to join other disabled children and young people in letting people know about what is important to you.   We will write a report of what everyone tells us. The report will mean that people who provide help or services have a better idea about the sorts of help children and young people really want.

Who are we?

Our names are Parvaneh, Bryony, Robina and Tricia: you'll meet one of us if you take part in the *'What Matters?'* project. We work at the University of York.   Our photos are on the back of this leaflet.

What does taking part involve?

If you want to take part in the *'What Matters?'* research project one of us will visit you at home (or somewhere else if you prefer). You might want to see us alone or have someone with you – you can choose.   We might also arrange a meeting so that young people living near each other can get together to think about things: you could come to that too if you wanted.

It's private and confidential

You can choose what you tell us: we will not tell anyone else. We will not use your name in the research project report.

Do you want to take part?

We hope you will want to take part in the research: **but it is your choice**. If you do not want to take part, that's fine. If you decide to take part and later change your mind, that's OK too.

What to do now....

There is a yellow form which came with our letter to you and your parent or guardian. If you want to take part in the research, please fill in the form. (You can ask a parent or another adult to do this for you.) There is an envelope for you to use to send the form back to us. We will get in touch once we have received the form.

Any questions

Do you want to know more about the project before you decide about taking part? That's fine. Get in touch with us and we'll try to answer any questions you have. You can get in touch by phone, letter or email to:

Parvaneh Rabiee, *What Matters'* Project, Social Policy Research Unit, University of York, Heslington York YO10 5DD.
Telephone: 01904-433608   email: pr15@york.ac.uk

Parvaneh   Bryony   Tricia

The 'What Matters?' Project
CONSENT FORM FOR CHILDREN AND YOUNG PEOPLE
(put a tick in the box to say yes)

Your name: …………………………………

☐ I have read the information sheet about the 'What Matters?' project.

☐ I have talked to……………….(one of the project workers) about the project.

☐ I understand what taking part in the project involves.

☐ I know that I can leave the project whenever I want to, and without giving a reason.

☐ I know that no one will mind if I leave the project.

☐ I know that anything I tell you will be kept strictly private.

☐ I know you will write a report about the project. This will include what I have told you.

☐ I know you will not use my name when you tell people what you found out in the project.

Would you like to take part in the *'What Matters?'* project?   **Yes/No**

Please sign your name here…………………………..

I ……………………… a member of the research team, confirm that I have told the above about this research project. I have given them the information leaflet. To the best of my belief, they have understood what I have told them and they are giving free and informed consent.

Signed…………………………………………   date………………..
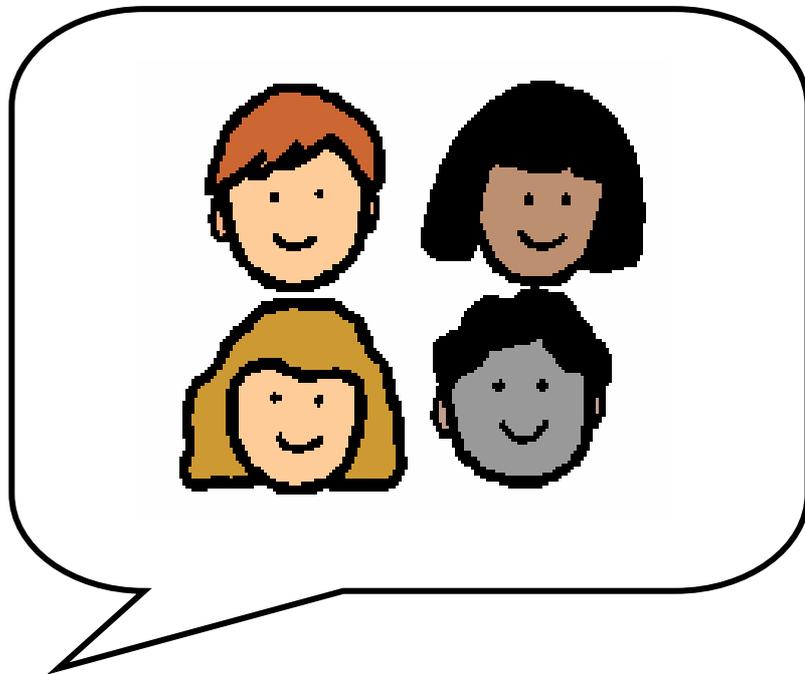
'WHAT MATTERS?'

Information leaflet for practitioners

The *'What Matters?'* research project

About the research
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Why are we approaching you?
Some children will not be able to directly participate in this particular project. We feel it is important to hear about the child from someone who knows the child well. Parents of children within the 6-18 years age band who are unable to directly participate will be asked to nominate another 'significant/valued/ liked person' in the child's life for us to interview. This might be the child's teacher, a respite care worker, link family parent,

worker on a play/leisure project, or a brother or sister of the child. These individuals will be invited to participate in the project and we will offer a face-to-face or telephone interview.

Covering costs

We will cover any costs you have through taking part in the research.

Confidentiality

The information collected during the research project will be treated with strictest confidence, and no-one taking part in the project will be identifiable in the project report or any other publication.

We find it helpful to tape record group discussions and interviews, but we would not do this if you would prefer us not to.

Deciding about taking part

You do not have to take part in this research: it is entirely up to you. You can also withdraw from the interview at any time without giving a reason.

If you are happy for a member of the research team to contact you about joining the project please complete the enclosed form. This can be sent to us using the envelope provided. We will then contact you and will be very pleased to answer any other questions you may have about the project. If you agree, we will also arrange a convenient time to visit or carry out a telephone interview.

Any questions?

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

       Parvaneh Rabiee
       Social Policy Research Unit
       University of York
       York YO10 5DD
       Telephone: 01904-433608
       Email: pr15@york.ac.uk

The '*What matters?*' Research Project

CONSENT FORM FOR INFORMANTS

This form is to make sure that we have explained everything that is involved in the research project to your satisfaction, and for you to state whether or not you agree to take part.

****

Have you read the information sheet about the 'What Matters?' Project and do you feel you understand what taking part in the project involves?   **Yes/No**

Have you talked to one of the project workers about the project?   **Yes/No**

Do you know that you are free to withdraw from the study at any time, and without giving a reason?   **Yes/No**

Do you know that all the information from the research will be kept strictly private and confidential?   **Yes/No**

Do you agree that the information from the research can be published if your identity is kept secret?   **Yes/No**

Would you like to take part in the 'What Matters?' project?   **Yes/No**

Signed _____   **Date** _____

Name _____

APPENDIX TWO

Topic Guides for Research Phase

INTERVIEW WITH PARENTS

1.   Preliminaries and introductions: suggested scripts

Thank you

Confidentiality

"We talked about confidentiality when we completed the consent form. I'd just like to remind you again that what you say is confidential and you and your family will not be identifiable in the reports of the research we produce."

Tape-recording

"I find it hard to listen and write at the same time and so I find it helpful to tape record the interviews I do. Would it be OK to record our interview? The tape will only be listened to by myself and other members of our research team. We will destroy it when we have finished using it."

*** *Switch tape on here if consent*

Introduction to the interview

"As we have explained in the information leaflet we sent you, the Department of Health has funded this research to find out from disabled children and young people and their families what outcomes they desire from social care/support services.
So we are interested in finding out what children and families want to achieve through services rather than what particular services they want.   The aim is for the professionals to use this information to build up a better picture of the sorts of help they should be providing and how they should be assessing whether their services are achieving what families want.

So what I would like to talk to you about today is to find out about the hopes and dreams/aspirations you have for [child's name], the opportunities and activities you want him/her to experience, and the sorts of help he/she and the rest of the family might need to achieve these things. "

2.   The child and his/her condition

If appropriate, could introduce in terms of not meeting child today and wanting to find out about the child and his/her condition. Parent might want to show a photograph or something.
Probe:
The child:
       Age, personality, appearance (e.g., hair, eyes, smile) favourite things etc.
The condition:
       Name of diagnosis and how that is manifest in terms of child's health and
       abilities
       Prognosis: what will happen in the future – will the condition develop, improve,
       deteriorate

Sources of information: who, where got this information from
(e.g. people – professionals, other parents, written info etc.)

## 3.	Everyday life

We will ask the parent to briefly describe a normal weekday for the child – waking up through to the end of the day. What child does, treatments/therapies, where child goes, after school activities.   Will then ask whether child goes to any clubs, what happens at weekends and holidays.

## 4.	Outcomes and aspirations

Using a visual display of the LAC dimensions (modified to be 'user friendly' and appropriate) as follows: your child's physical health; being at school; how your child feels about him or her self (includes: self-confidence, maturity, emotional well-being); your child's relationship with other family members; your child's relationships with other children/young people of the same age; your child's relationships with other adults; the way your child looks (i.e. clothes, equipments)*;* communicating and being able to make choices; activities and experiences; gaining the abilities to look after him/her self and becoming independent

a.	BRIEFLY, explain the display (E.g. something like "….a way of looking at a child's life and the different things that make it up…; some bits more relevant to some children than others, depending on age/nature of impairment or condition").

Separately, for each dimension
b.	Explain what the dimension is (perhaps giving examples)

c.	The role services currently play in this dimension of the child's life (KEEP BRIEF: the interview goes back to service quality later)
	Probes:
	- Type/name of service(s)
	- Perceived benefits/good aspects/positive effects of service(s)
	- Perceived disadvantages/bad aspects/negative effects of service(s)
	- Perceptions of whether services have a role to play in this dimension of the child's life

d.	Ideally, what would you like for your child – achievements, opportunities?
	Probes:
	- The role of services (if any) in achieving that outcome
	- Specifically, the types of help that would be needed in order for child to achieve outcome/be enabled
	- If a number of different things mentioned within a single dimension: Are any more important than others?
	- Identifying whether short, medium and long term outcomes: encourage exploration all time-scale outcomes. In some cases this might be just to establish why cannot think medium/long term.
e.	Finish off this bit by reflecting on the 'display'. Is there any thing missing/is there a new/different dimension that should be included on the 'display'

5.   Exploring service quality

Ask parent to describe a specific service their child uses. (We could say tell us about the best or the worse). Explore good and bad specific to that service and ways it could be improved (e.g. *'What would make it a better service?'*).

Then broaden out – anything more generally that is important for service quality

> *Possible probes:*
> - staff - skills
> - staff – attitudes
> - interactions between child/professional/parent
> - communication/information/honesty
> - place where service delivered: access, present in community
> - choice./flexibility
> - inclusive/mainstream vs specialist

6.   Services currently used by the child/family

[*Alert parent that interview drawing to a close*]

Parents will be shown a checklist of the range of services/professionals that might be providing a service to the child/family. Parents will be asked to indicate which services they use/receive. The list will include: therapies, health care/nursing, school, short term care, play and leisure, community equipment, wheelchair, housing adaptation etc..

7.   Close

Any questions

Thank you

Remind re focus group – establish whether, in principle, interested; where language likely to be an issue ask for preferences in terms of the type of group want to attend. Offer individual interview as an alternative.

Where child may be involved, discuss child's involvement and preliminary consent, communication needs etc.

If necessary take/collect/arrange to receive photos to use in child's interview.

Arrangements for making contact re interview with child

INTERVIEW WITH CHILD/YOUNG PERSON

NOTES
The topic guide below outlines the entire interview. It may be necessary to complete the interview over more than one session. The format of the interview is constructed in such a way to make it easy to 'split' the interview. In addition, the visual nature of facilitatory activity will mean it will be easy to recap the first session at the start of the second session.

This form of the topic guide will be used for the interviews with those children able to fully participate. Notes on how the interview will be conducted with those who will only be able participate in a limited way can be found at the end of the schedule.

PRELIMINARIES
i) Recheck consent

i) Remind that it is OK to stop interview at any time, or not to answer a particular question.

ii) Rehearse with child various strategies (whatever seems appropriate) for stopping interview or not answering question

For example:
* using red and yellow cards (perhaps with something written on)
* choose a phrase to use if want to stop
* choose a phrase to use if don't want to answer a question
* can use a silly word if don't want to answer a question
* squeaker

iii) Ask permission to tape record. Offer child chance to listen back. Or the chance to ask some questions (to the interviewer) later on.

If OK, switch on TAPE MACHINE and MICROPHONE

INTRODUCTION
i)   Thank you
Thank child for agreeing to take part.

ii)   If necessary record verbal consent or state consent has been obtained.

iii)   Stress there are no right or wrong answers

iv)   Stress the study is about finding out about children and young people's views and experiences. There are no right or wrong answers. We are just interested in what you think and feel about things.

THE INTERVIEW

Facilitatory tool/activity

1.   Largish piece of board with a central circle and a number of circles to stick onto board stemming out from central circle. Central circle represents the child and the other circles represent different areas of the child's life. This will be informed by what we have learnt about the child from the interview with the parent. The areas represented by the circles might include: family, home, looking after myself (i.e. self care), people who look after me, equipment I need, school, friends, things I do after school, things I do at weekends and holidays, places I stay (i.e. residential care, Link family), treatments and therapies, moving about.

2.   Pens and crayons for writing/drawing; glue/bluetack

3.   As an alternative to writing/drawing: Boardmaker symbols (and other pictures not featured within Boardmaker – this could include places/people and activities specific to the child) for 'sticking' onto the various areas to show the things/people etc which make up the child's life.

1   DEVELOPING A MAP/PICTURE OF THE CHILD'S LIFE

Using materials described above make a 'map' of the child's like to get a brief factual description/overview of the different areas of the child's life.

Begin with the central circle: invite child to draw themselves, write their name, stick on a photo etc.)

Introduce circles for sticking on the map and obtain basic information for each.   Use Boardmaker symbols/writing/ drawing to display this information on the 'map'

For example:
Home circle: just the address or a drawing of the house

Family: names and relationship to child

Self-care: things child needs help with re bathing showering etc.

Treatments/therapies: list of types and when/frequency of doing

School circle: name of the school

Equipment: list of equipment
People: just names and what they do.
Friends: names, where see them
Things I do after school/things I do at weekends etc: activities, clubs etc.
Moving about: wheelchair; use of public transport, school transport

2a   IDENTIFYING THE POSITIVE AND NEGATIVE AREAS OF THE CHILD'S LIFE

Using the 'picture' as the focus and prompt for discussion work with the child to identify the positive and negative areas. The focus on each 'circle' in turn.

Ask child to give each circle a rating of how good/bad it is. For example by giving a circle a score: 'marks out of ten'; or a dial; or a rotating thumbs up/thumbs down indicator.

As each circle is given a rating explore why like/dislike

> ***Possible probes to understanding why like/dislike (use of these will depend on what is being talked about):***
> a) *The specifics of the activity* (break it down: Can you tell me one bad/good thing about it?; Can you give me an example of what you don't like?)
> b) *How it makes the child feel* (e.g. happy/sad; pleased/proud; embarrassed, lonely, wanted, comfortable, etc...)
> c) *Nature of the experience* (for example: boring/interesting, exciting/scary, difficult/easy, enjoyable etc)
> d) *Physical experience* (pleasant/unpleasant; painful)
> e) *Social aspects*: what the people are like/ they way they treat the child
> f) *Physical aspects* of the place/location

2b   EXPLORING WHAT WOULD MAKE IT BETTER

This will lead from discussion about the good and bad bits and exploring how the circle could be made better.

Looking at the things the child has identified as liking/disliking within that circle:
Explore whether want changes or improvements, or got rid of etc..

> *Possible facilitatory activities:* To facilitate this could use activities such as putting things in a bin (..but this would mean removing an entire circle from the board), or giving a red card to things want to get rid of; sticking on symbols of a first aid box/plaster to things/areas want to change/improve.

> *Possible prompts:* phrases such as 'Can you tell me one thing that would make this better for you?'; 'If you were in charge how would you change it?'

Where possible or if not apparent, try to probe the reason behind suggested changes:

> *Possible probes (their relevance will depend on the thing under discussion):*
> a) Independence/enabling (for example: I want to do this but I want to be able to do it without my mum helping).
> b) Social interaction: presence of other people would enhance/improve (for example: Enjoy swimming but would like to do it with friends)
> c) People - attitudes encountered; involvement in decision-making, given choices
> d) Place/location – in order to look at aspects of the physical environment and issues of access (e.g. Enjoy swimming but changing rooms difficult)
> e) Time – when something happens (either in terms of time of day, or day in week or time of year).

3 NEW EXPERIENCES AND OPPORTUNITIES

Adding to the picture: what would the child want to see on the picture that's not there now?

  Probe: activities, people and places

Child might like to draw things to stick onto the picture, or could have a series of blank outlines of magic wands or stars for writing/drawing on then sticking on to the picture. Another tool might be to use 'chance cards' onto which write/draw things child would like to have a chance to do and then place on the 'map'.

4 ASPIRATIONS (FOR 12 – 18 YEARS AGE BAND ONLY)

Use a time line to show young person now and young person 'as an adult/grown – up': young person can define actual age.

Time line activity: this is me now and this how I'd like to be when I'm an adult. 'Label' the time line to describe 'aspired adult self'.

  Probe: where living; who living with; work/study/employment; spare/leisure time.

Once drawn explore barriers to achieving aspirations and things that will support achieving them. These could be drawn onto the time line – perhaps different colours.

  Probe the role of:
  Parents/family
  Professionals/services
   - school
   - social care services
   - other
  Types of support needed
  Issues of planning – perhaps draw on to the time line when this should start happening.

5 Lightening up activity
  (What are the three most important things in your life?)

6 Close
  Any questions?
  Remind re picture and report
  Remind re contact: contact card
  Thank you
  Token

Tools
Board
Circles
Any necessary photographs specific to the child
Pens, pencils, crayons, rubbers, bluetack, glue stick
Paper: various sizes
Blank time line
Rating tools: dials; thumbs up/down thing.
Blank magic wands/stars/chance cards

First aid box/plaster/red card symbols
Bin for putting bits of life want to get rid of.

Modifying the topic guide/interview schedule for those whose participation is at a more concrete or basic level

The interviews with children/young people whose cognitive and/or communicative abilities will mean we need to adopt a more simple and concrete approach will take place after the interviews with the cognitively more able children.

The data gathered from the interviews using the topic guide described above will inform and generate content and materials for these later interviews. For example, the range of responses to a particular issue provided by the 'fully participative' children could be then offered as a series of choices (presented in a visual, symbolic form) in the more 'basic' interviews.

More concrete symbols (i.e. taking less of a rating scale approach) for use in later interviews include: smiley/sad faces; gold stars; ticks and crosses; thumbs up/down.

Sample Topic Guide for Focus Groups with Parents

FOCUS GROUP
PRIMARY SCHOOL AGED CHILDREN WITH ASD

Refreshments available at 6:45

7:00 Preliminaries (10 mins)

- Thank you
- Practicality- time we stop, expenses, what we are going to do and how, where the loos are.
- Permission to tape record
- Ground rules (A3 sheet) – pin up and invite additions
    - This group will respect each other's views
    - We will listen to each other
    - We will give people time to have their say
    - We will treat what is said as confidential
    - It's OK to pop out for a break if we need to
    -
    -
    -

7:10 Introduction (10 mins)

- Remind the purpose of the research and this session in relation to that.

[As you may remember, the Department of Health has funded this research to find out from disabled children and young people and their parents what matters to them and what outcomes they desire from social care and support services. The aim is for the professionals to use the information we gather to build up a better picture of the sorts of help families really want. I have already met you individually where you talked about the outcomes you desire for your children. The purpose of this focus group is to explore your views on what you want to achieve through services for yourself to help you with your caring role. In the next stage of the project, we want to develop practical ways by which social care providers can tell whether the services they provide are enabling disabled children/young people and their parents to achieve the outcomes they desire.]

- Introduction to each other – each person to introduce self, say a little about themselves and their child, e.g. age of child.

7:20 Warm up exercise (10 mins)

Exercise to remind people about outcomes – i.e. outcomes are what they want to achieve for themselves. Give the group a non-service related example to think about outcomes:

"You've got the chance of having a day off from looking after the children. You want to end the day feeling rested and relaxed – what would you do to achieve this?"

- There are lots of different ways in which you might achieve this – brainstorm – how would each of you achieve this – point out differences, no one way of getting to an outcome.

- What we want to do *first* is think about the outcomes you want, rather than how to get there. Then we will think about how to achieve these outcomes and what role services should play.

7:30 Completion of pie chart exercise (10 mins)

[give example of own pie chart]

Individuals to chart:

My life at the moment
How I would like my life to look
[10 mins to do this, put name on charts]

7:40 Sharing and discussing pies (25 mins)

- Each person pins up their chart and explains it.   We might need to probe for explanations.

- Once all pinned up – sum up and open for discussion. Things we might want to probe are: unpicking time for me, asking about siblings needs, defining what quality family time might mean.

8:05 Exercise: achievements for the year (10 minutes)

- Each person given a large sheet entitled: "By the end of 2003 I would like to have achieved…."
    1.
    2.
    3.

- Explain that these will be shared within the group afterwards.

8:15 Feedback on achievements (10 mins)

- Each person pins up in turn, commenting if they wish
- Pull together/make observations

8:25 Discussion: how to achieve these aims (20 mins)

- What do you need to help you achieve these things
  - Including services (including things not currently provided), the way services treat you
  - Non-service type things
  - Encourage lateral thinking/solution generating.

8:45 Group discussion: Messages to services (10 mins)

- What are the messages to services from this
- If you were in charge of services/had a magic wand to change things – what would you do?

8:55 Close

- Thanks
- The next steps – advisory group for next stage
- Tokens and expenses

9:00 End of meeting

By the end of 2003 I would like to have achieved….

1.

2.

3.

APPENDIX THREE

Tools to Facilitate Interviews in the Research Phase

Tool for interviews with parents

Doing things for himself and becoming independent

My child's relationships with other children/young people

My child's health

The way my child is seen by other people

MY CHILD

Being at school

My child's relationship with other adults

My child's relationships with his family

How my child feels about himself

33
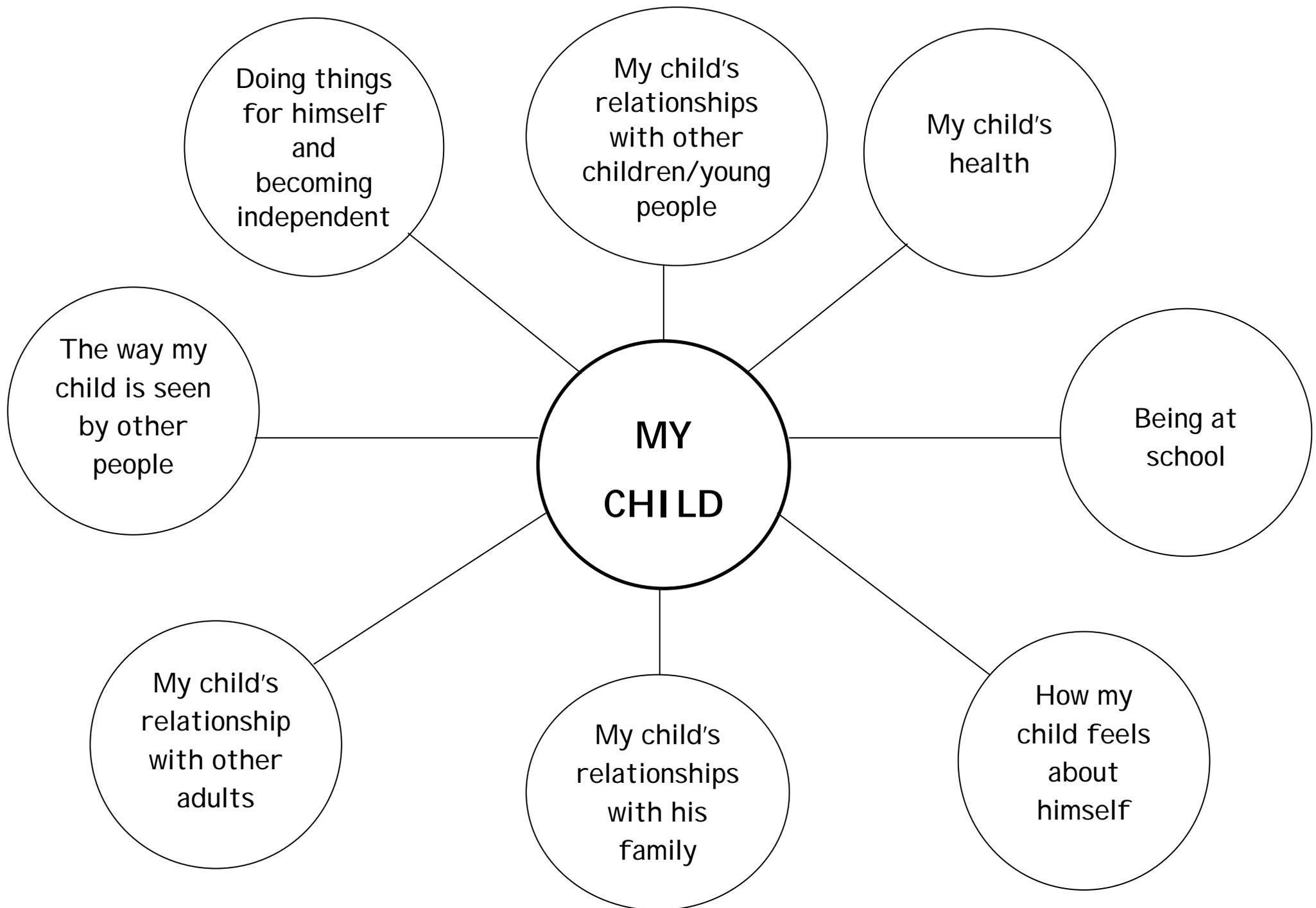
**Example of tool used with children
who do not use speech**

My communication aid

Sam

Sam wants his communication aid to be faster
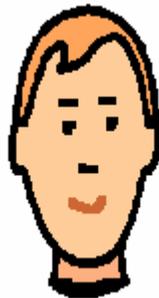
Adam

Adam wants his communication aid to be able to say more things

George

George wants to be able to use his communication aid wherever he is

John

John wants to have a communication system he can use without help

35

How do I want my doctor to talk to me

Lucy

Lucy wants her doctor to talk to her in a way she understands

Julie

Julie doesn't want her doctor to talk to her

Ayesha

Ayesha doesn't mind

Communication Questionnaire

Completed by parents of children who do not use speech
to communicate prior to interview

HOW MY CHILD COMMUNICATES

We want to make sure your child can take part in the 'What Matters?' in the way that suits them best. Your answers to these questions will help us to do that.

1. Does your child have "good times of the day" when they find taking part in things easier?

   _____

   _____

2. **Please tick which best describes your child's level of attention when doing something they enjoy.**

   ❑ Attends only briefly

   ❑ Attends for 5 minutes or more

   ❑ Is generally attentive

3. **How would you describe your child's hearing?**

   ❑ Good   ❑ Adequate   ❑ Poor

4. **Does your child have any problems with their sight?**

   ❑ Yes   ❑ No

   If 'yes', please tick the following

   Can your child…

	Yes	No	Don't know
make their eyes work together?	❑	❑	❑
follow a moving object up and down with their eyes?	❑	❑	❑
follow a moving object left and right with their eyes?	❑	❑	❑
maintain gaze on a fixed target?	❑	❑	❑
Does your child have a limited visual field?	❑	❑	❑

   If yes, please explain… _____

   _____

   _____

5. Does your child have a clear way of…

- ❏ communicating 'yes' and 'no'
- ❏ providing information ("telling someone something")
- ❏ asking questions

6. Please tick ALL the ways in which your child communicates

- ❏ facial expression   ❏ making sounds
- ❏ eye gaze   ❏ speech
- ❏ gesture

- ❏ signs

    - ◆ which sign vocabulary/language does your child use?
      _____

    - ◆ approximately how many signs do they use? _____
    - ◆ can they put signs together (e.g. 'daddy car', 'daddy wash car' etc.)
      _____

    - ◆ approximately how many signs do they understand?_____

- ❏ graphic symbols

    - ◆ what type of symbols does your child use?
      _____

    - ◆ approximately how many symbols does your child use?_____
    - ◆ how are the symbols presented? (e.g. charts, communication
      book)
      _____

    - ◆ how does your child indicate which symbol they want?
      _____
      _____

- ❏ speech output device

    - ◆ which device(s) is/are used? _____
    - ◆ what (if any) standard vocabulary package is used with it? _____
      _____

APPENDIX FOUR

Methods Papers

Long title:

Doing research with children and young people who do not use speech for
communication

Short title:

Research with children who do not use speech

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Doing research with children and young people who do not use speech for communication

Abstract

Despite emphasis in policy on participation of disabled children[1], we still know relatively little about how to obtain the views of disabled children with significant communication impairment and their views are often overlooked in planning and service provision. This article describes how the views of children who do not use speech were accessed in research aiming to identify disabled children and young people's priorities regarding outcomes of social care and support services. The main challenge was to develop a method that was reliable, non-threatening, enjoyable and relevant to individual children, as well as enabling children to think beyond their everyday life and express what they aspire to.

Introduction

Research shows that disabled children have been largely excluded from consultations and involvement in decisions, which affect them (Morris, 1999b; Morris, 1999c; Cavet and Sloper, in press). Particular exclusion has been experienced by the children and young people who do not use speech as their first mode of communication and/or are perceived as having significant cognitive impairments (Morris, 1998a; Morris, 2003). Underpinned by medical discourses, children who do not communicate using speech have been and continue to be defined by what they cannot do, rather than what they can. However, there is a growing body of literature, which indicates a whole range of communication strengths and a great willingness and ability on the part of disabled young people to communicate their feelings and experiences and be involved in a process of change (Disabled people using Scope services, 2002; Rabiee and others, 2001; Morris, 1999a; Stalker and others, 2003; Watson and others, 2000; Cavet and Sloper, in press). A report written by disabled people with communication impairments provides many interesting and powerful remarks by disabled people about their communication impairments. While acknowledging that they do have communication difficulties, they believe they have qualities which give them communication strengths such as perseverance, patience, being able to read other people's communication, pointing out things they want and using yes and no in different ways (Disabled people using Scope services, 2002).

Recent policy developments of the 1990s have raised general awareness and placed legal obligations on society in general for improvements in the provision of services for disabled people. Within this larger policy context there is a growing recognition of the need to consult children and involve them in decisions about their lives. The UN Convention on the Rights of the Child emphasises children's rights to receive information and express their views about matters that affect them and

---

[1] For brevity, the term children is used to cover children and young people up to 18.

Article 13 directs attention to the need for appropriate means of communication to be provided for children. The Children Act 1989 and Quality Protects (Department of Health, 1998) both stress the importance of ascertaining the wishes and feelings of children, including disabled children, and involving them in decisions about their care and welfare, and the Department of Health (2002) has also issued guidance underlining its commitment to involving children in all aspects of its work. Most recently, the National Service Framework for Children Standard for Hospital Services (Department of Health, 2003a) sets out standards that all hospital services should meet, including

> 'They [children and young people] should be encouraged to be active partners in decisions about their health and care, and, where possible, be able to exercise choice.
>
> Children, young people and their parents will participate in designing NHS and social care services that are readily accessible, respectful, empowering, follow best practice in obtaining consent and provide effective response to their needs.' (p. 9)

Both Department of Health (1991) guidance and the recent National Service Framework for Children Emerging Findings (2003b) make it clear that provision should be made to involve children with communication difficulties in decision-making.

Despite this emphasis in policy objectives on participation of disabled children/young people, evidence suggests that while in general children are more involved in the process of decision making, disabled children's participation has been more through other agents than being direct (Council for Disabled Children, 2000; Sinclair and Franklin, 2000; Robbin, 2001). Therefore our knowledge of their experiences is still largely second hand knowledge given to us by adults whose views and experiences may differ from those of the children (Beresford, 1997; Mitchell and Sloper, 2001; Thomas and O'Kane, 1998)

The key issue is that we still know very little about how to involve this diverse group of children in areas affecting their lives. Fundamental to achieving the overall aim of participation is therefore to develop communication methods, which can maximise children's communicative potential to express themselves and address the barriers they face. The other key component for effective participation is to recognise the fact that communication is a two way process requiring others to learn and understand how a child expresses her/himself (Triangle/NSPCC, 2001). As a disabled child with communication impairment has put it:

> 'We are used to people saying we cannot communicate, but of course they are wrong. In fact we have powerful and effective ways of communicating and

we usually have many ways to let you know what it is we have in mind. Yes, we have communication difficulties, and some of those are linked with our impairments. But by far the greater part of our difficulty is caused by 'speaking' people not having the experience, time or commitment to try to understand us or to include us in everyday life' (Disabled people using Scope services, 2002, pp.1-2).

This statement is supported by service providers' own concern about the difficulties they experience in communicating with this group of children (Council for Disabled Children, 2000). For the children who use Alternative and Augmentative Communication (AAC), this would mean adequate training and support not only for children who use the system but also for staff and AAC users' peers (Clark and others, p.108). What is encouraging is that more and more interest is being shown by local authorities in using innovative consultation methods for consulting disabled children and undertaking staff training (Council for Disabled Children, 2000).

In research, there has been increasing recognition of the fact that children's views differ from those of adults and there is now a body of research, which has obtained the views of disabled children. This research has shown that disabled children hold and can express views, given the right environment, and that they value participation (Cavet and Sloper, in press). Therefore, the exclusion of disabled children from research and consultation says more about unsuitability of research and consultation methods and adults not knowing how to relate to them than about the limitations on the part of informants. For example, as Argent and Kerrane (1997) have noted, '…'they don't understand', often means 'I can't think how to explain it to them'' (p.73). Similarly, Booth and Booth (1996) suggest that '… researchers should attend more to their deficiencies than to the limitations of their informants' (p.67). Unless appropriate tools are found this group of children may remain largely unaffected by all the policy advances made for children.

The project and what it is seeking to do
This paper has arisen out of a four year research and development project funded by the Department of Health to identify the priorities and perceptions of disabled children and young people (0-18 years) and their families regarding outcomes of social care and support services (the research phase), and to develop tools by which these desired outcomes can be assessed or measured (the development phase). The project works with four groups of disabled children who are identified as 'difficult to reach' and causing concern for service providers. This includes children and young people with complex health care needs, communication impairment, autistic spectrum disorders or degenerative conditions. The fieldwork has been carried out in three local authorities and involved interviews with children (if 6 years or over) as well as their parents to identify the outcomes children want for themselves and those that parents want for their children and for themselves.

Previous research involving disabled children has highlighted the importance of identifying their communication needs for participation and adopting a flexible approach in meeting these (Morris, 1998; Marchant, 1999; Beresford, 1997; Ward, 1998; Watson and Priestley, 2000).

There is a growing body of literature detailing successful approaches to involving children with communication impairments in the process of decision making (e.g. Morris, 1999b). Some of this work aims to improve practice in communicating with this group of children, by offering advice and information to those working with them (Morris, 2002; Triangle/NSPCC, 2001; Warrick, 1998).

There is also some interesting work to support the process of obtaining the views of children and young people with communication impairment, for example a practical 'tool kit' of cards (Kirkbride, 1999), talking mats (Murphy, 1998) and a training video for practitioners (Triangle/NSPCC, 2001).

While these studies have provided useful insights about the life experiences of disabled children, they have mostly explored children's experiences in terms of likes and dislikes specific to certain current situations. The exception to this is a tool called an image vocabulary, developed by Triangle (Triangle/NSPCC, 2002), which aims to enable children to communicate more complex issues, for instance about feelings and safety. Nevertheless, we still know little about how to obtain the views of disabled children with significant communication impairment on more complex issues, such as what they aspire to achieve and experience, for which there may be no appropriate symbols. There is even less progress made in seeking the views of children/young people with communication impairment who are also perceived as having learning difficulties (Morris, 2003).

This paper explores the method used in this project to access the views of children who do not use speech to communicate about outcomes they want to achieve through services. The most challenging task has been to find out how to deal with the difficulties of understanding what outcome is. By outcome of a service, we mean the impact or effect on the child's life (Nicholas, 2003), rather than just the provision of service. With outcome being an abstract concept, the question was how to break down the concept to make it easier for the children to grasp it, so that we could go beyond what they liked and disliked to explore what really mattered to them and what they aspired to achieve and experience.

The main methodological issue in working with this group of children is giving them the opportunity to participate. To fulfil our research question the method had to be reliable, non-threatening and an enjoyable experience for the child. It also had to be both concrete and relevant to the individual children being interviewed. In keeping with the principle of inclusivity, another key dynamic was the flexibility of approach so that it could be adapted to different ages, needs and abilities of the children involved

in the project. While we used visual techniques when working with all children, we had to use different approaches depending on the children's cognitive and communicative condition.

Development of methods
We adopted the ideas of the 'talking mats' (Murphy, 1998), a visual framework using symbols to help people with communication difficulties to communicate, as a basis from which our research tool was developed. To access children's views about outcomes they wanted to achieve through services, the first task was to identify areas of child's life we would need to cover in the work with children who do not use speech as their first mode of communication. To do that we began with interviewing children with complex health care needs who used speech and were able to fully participate in interviews and their parents. The rationale for starting with this group was that while they had some similarities in terms of their health conditions and contacts with services, they were likely to provide the most depth of information. However we were aware that the issues relating to communication were not likely to come up as much in those interviews. To cover that and also to obtain a deeper understanding of the areas important in the lives of these children we then interviewed parents of children who do not use speech. The data generated from all these interviews then informed the content of and approach taken in interviews with children who did not use speech for communication and, in the majority of cases, had more limited understanding.

The interviews with parents centred around their views on the outcomes they desire from social care/support services for their child(ren). Similarly, interviews with children centred on their hopes and aspirations for their lives. We also asked parents and children (wherever possible) about the kind of help and support they felt was needed in order to achieve those outcomes. To support participation in direct work with children, we obtained background information about the child's abilities and what facilitated their communication by asking parents to fill in a questionnaire. This showed that the majority of these children were familiar with the use of the Boardmaker symbols, which we then used in our work.

Based on these interviews, we identified eight main themes to explore: communication, friends, school, independent skills, mobility, looking after the child when they are away from their parents/carers, activities and social presentation (the way in which child's appearance and impairment is perceived by the outside world). We asked different questions relating to each theme to know what a child aspired to in different areas and how this related to what they were experiencing currently. Having identified the main themes and the areas we wanted to cover, we again used the interview data to generate statements for each area of the child's life, which represented opposing and ambivalent views, using different characters. For example: based on the area of 'How do I want my doctor to talk to me', the statements were:

'John wants his doctor to talk to him in a way he understands', 'Adam doesn't want his doctor to talk to him' and 'Naeem doesn't mind'.

The interviews were facilitated by using A4 laminated cards. The area of the child's life was presented at the top of the card with an accompanying symbol(s). Symbols chosen were as close as possible to the area of life represented, but what was most important was the meaning we ascribed to a symbol and the words/phrases which we used to name symbols for the purposes of the interview. We used simple symbols and words.

INSERT FIGURES 1 AND 2 ABOUT HERE

The cards were presented in two forms:
- For some areas, the lower half of the card showed three or four characters (faces and names) – each 'assigned' to one of the statements (see Figure 1). The characters changed and the order of the statements/options (i.e. positive, negative, and ambivalent) was varied to avoid any response bias. Every card had an Asian character included. Children were asked which character's statement was most like them and chose only one statement.
- For other areas, the lower half of the card showed different aspects/sub-areas of the overall area/issue. For example, based on the area of 'My communication aid' the statements were 'Sam wants his communication aid to be faster', 'Adam wants his communication aid to be able to say more things', 'Naeem wants to be able to use his communication aid wherever he is' and 'John wants to have a communication system he can use without help'. Here the child could have multiple choices and take as many statements as s/he wanted (see Figure 2).

We used two sets of A4 cards, a male version and a female version and a mat with the child's name on to make it more personal, on which the child could stick their chosen statement, building up a picture of how they would want their life to be. The cards were made colourful to make them more interesting. To engage the children more and make it more interactive we made separate labels for the statements and attached them to the cards using Velcro. This gave a chance to the child to get more involved by taking off his/her chosen statement and sticking it on the mat.

For both types of presentations we had some additional questions to further explore the issue. While for some, depending on their cognitive ability and access to communication systems, this was limited to asking a question like 'is that what it is like for you now?' which only required a yes/no response to find out whether what they wanted was different to what they currently experienced, for others we could ask other questions requiring more detailed responses. We carried extra symbols and blank cards on which we could make instant symbols if needed in such cases. In all interviews we were sensitive to the non-verbal behaviour children used such as facial expression, vocalisation, eye pointing and body movement.

Some of the statements were accompanied by a series of sub statements, for example, going out 'on the bus'. While one card asked whether or not the child wants to go out on the bus, the accompanying card asked who s/he wanted to use the bus with. This was only asked if the answer to the first question was positive.

Using the tool
Characteristics of the children
Eleven children with complex health needs (CHN) and seven children who do not use speech to communicate (NS) took part in interviews. Twenty-six parents of CHN children and 24 parents of NS children were interviewed. The tool was used with seven NS children who were between 6 and 18 years of age. While none of the children communicated using speech, the majority had a number of different impairments including cognitive and/or physical impairments. The group did not include children who could speak but, for whatever reason, chose not to speak, and children whose sole impairment was being deaf. To keep the focus on the issues, which were more specific to communication impairments, we excluded from this group children who were included in the other study groups, that is children diagnosed as having autistic spectrum disorders and children who had degenerative conditions.

Similarly to other researchers (for example, Morris, 2003), while seeking to identify potential research participants we were often confronted with negative attitudes from gatekeepers about the child's communication abilities. We were told statements such as 'he/she is not able to participate', 'you will not get anything out of him/her' and 'there is no point in asking him/her any question, I could tell you everything you would want to know'. We were often told that for children classed as having learning difficulties their level of understanding was too limited for taking part in the research project. However, in keeping with the principle of the social model of disability we identified the research sample by explaining what taking part in the research involved and discussing how the child would be able to cope with that task. Indeed we later found out that had we gone by the label used for the child, the majority of children we included would have been excluded yet again from research.

In terms of communication, some of these children used technological communication aids (computer assisted system) such as Dynavox communicator, a few used sign language and low-tech aids, such as a talking book or communication board. One used a computer at school and signed at home. All of them relied on more than one method to communicate and used facial expression, eye pointing, body movement and vocalisation.

Managing reliability and level of understanding
The data obtained would only be useful if we could ensure that the children understood the questions and their answers were likely to be reliable. To investigate this we started the interviews with three practical questions, based on the

background information we had previously acquired from parents. We used very simple questions (for which we had information from parents on whether the child would be able to answer and in some cases what the child's answer would be) using the same mechanisms as for the main research questions. In the first instance, where we wanted to know whether children were able to use the tool and their answers were factually true, we asked the child how s/he went to school. To test the child's ability to answer the question by picking more than one statement/option, we asked what food he/she would most want to have for dinner, where they could pick more than one option. To test whether they understood the concept of wanting/ aspiring (as against currently experiencing something) we asked them what they would most want to do, making sure their favourite activity was there. If at this stage we were not confident that the child understood the questions and that responses were reliable, we would not proceed any further with the interview. This happened with one of the children we approached. The fact that children used a combination of methods to communicate simultaneously was another means by which we double-checked the reliability of their answers throughout the 'interview'.

Children were interviewed on their own unless it was considered useful to have someone who knew the child well to be present to facilitate communication and/or be there as a support for the child. Child's assent was always obtained in those cases. However, on a number of occasions this person left the interview shortly after it had started because there did not seem to be a need for it any longer.

Prioritising the statements for those with limited attention or ability
A number of things had to be done prior to each interview. For example, we had to change some of the questions to make the cards more relevant to children's individual lives. For example, when the child did not have residential respite but went to a club; we changed the area and statements to what was relevant to the child. Some of the questions were not relevant to some children (e.g. missing school due to treatments) so we would take them out of the pack before the interview. We also prioritised the cards, to help us in situations where the child was not able to go through all the cards for whatever reason.

Where the interviews took place
Individual interviews with parents took place in their home (with the exception of one), but the interviews with children were held at venues recommended as appropriate for the child by the parent/carer. We visited some children within their family setting, some in respite centres and some in schools where the child was said to have a better access to a communication aid and support. Some interviews were held at school because the child was said to be more alert and responsive in the school environment. Some children/young people were interviewed during weekends, some in the evenings and some during school holidays.

Time taken

The interviews with children took between 45 minutes and one hour 15 minutes. In addition, for every interview, we spent at least half an hour with the child, prior to the interview; in whatever environment the interview was taking place, prior to the interview. This not only maximised the child's confidence to express themselves but also our confidence to understand their way of communication better. Where the interview was in school, we used the opportunity of spending time with the child during the break time.

Reflections/conclusion

Key features of this tool are the ease of use of these cards and particularly the fact that its format is non-threatening for children. Young people found it entertaining and fun and appreciated the interactive aspect of being able to control what they chose in response to the questions. Even where children had limited control over their body movement, as is often the case with those having cerebral palsy, they insisted on taking part in doing the activity. In two cases, the person who was present (in one case the child's mother and in another case the school assistant) helped keep the child's arm up in order to enable them to physically pick their chosen option and place it on the mat. Again, the fact that children simultaneously used a combination of methods to communicate helped us check the reliability of their answer in those circumstances and ensure that the response was not prompted by the helper.

While the technique worked for all the children in relation to finding out their choices, with some children, it was possible to further explore some of their underlying reasons for wanting or not wanting certain things. For example, where one child said she does not use public buses but wants to do so, she told us, using signs, that it is climbing and steps that makes it difficult for her.

We were told, on various occasions, that this was quite a new experience for the child involved because very often a disabled child is not used to having choices or expressing their opinion. For example, in one of the interviews with a child where her support assistant was present, the child looked at the assistant every time she was asked a question. The assistant commented that this was because they were not everyday questions and the child must be wondering why I was asking these questions from her and not the assistant, because the assistant would know the answers anyway. Later on she told me that this happened all the time and one of their aims in the school was 'to teach children not to rely on other people to speak for them'.

Indeed we felt that this was not just a new experience for children. Some parents and teachers were pleasantly surprised to see the child getting so much involved and expressing choices. One mother (whose child was diagnosed as having severe learning difficulties) told us she never thought her son could concentrate for so long. A teacher who was present in another interview was also surprised when she

noticed that one of her pupils was taking interest in the work and paying attention to what was going on and responding so eagerly.

Despite all our efforts to ease communication, there were times we encountered difficulties. For example, children refusing to respond because they were in the middle of watching a favourite video or they had an argument with someone or they just felt tired. This was largely overcome by either staying a long time with the child, giving them frequent breaks or making repeat visits (within the resource constraints of the project). In many cases, further information from a parent or carer helped to overcome these problems. It was important to learn from every interview and take this learning into account when planning subsequent interviews.

Comment on wider applicability

The method described here has much wider applicability in both research and practice. It could be expanded and adapted for use in different settings (health, social services, education, and private or voluntary sector agencies) where the professionals want to seek the views, and assess the needs, of children and young people who either do not use speech for communication or use speech in a limited way.

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Figure 1: Example of card used in interviews

How do I want my doctor to talk to me

John

John wants his doctor to talk to him in a way he understands

Adam

Adam doesn't want his doctor to talk to him

Naeem

Naeem doesn't mind
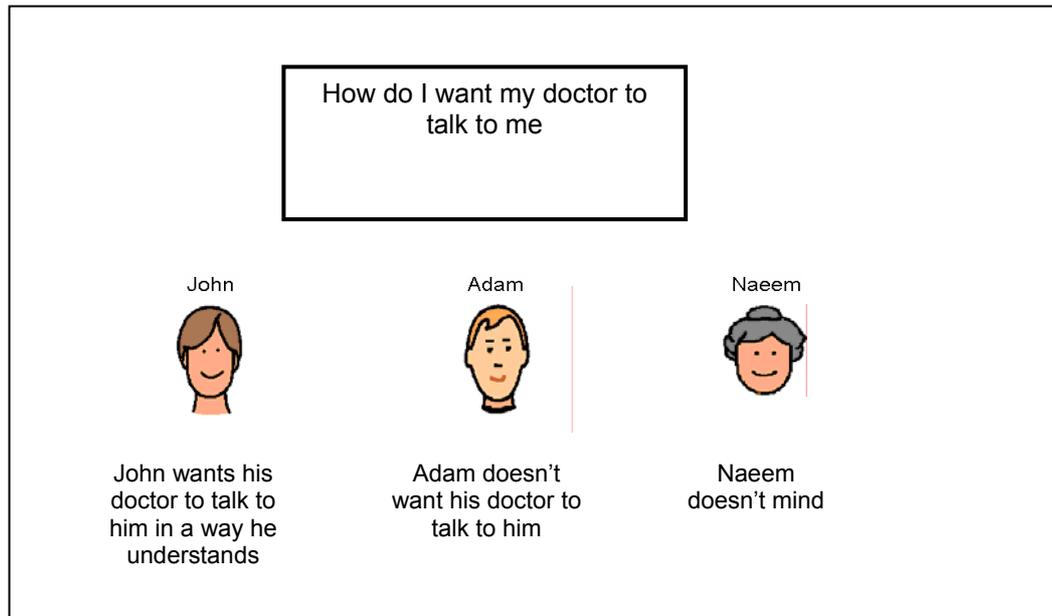
Figure 2: Example of card used in interviews
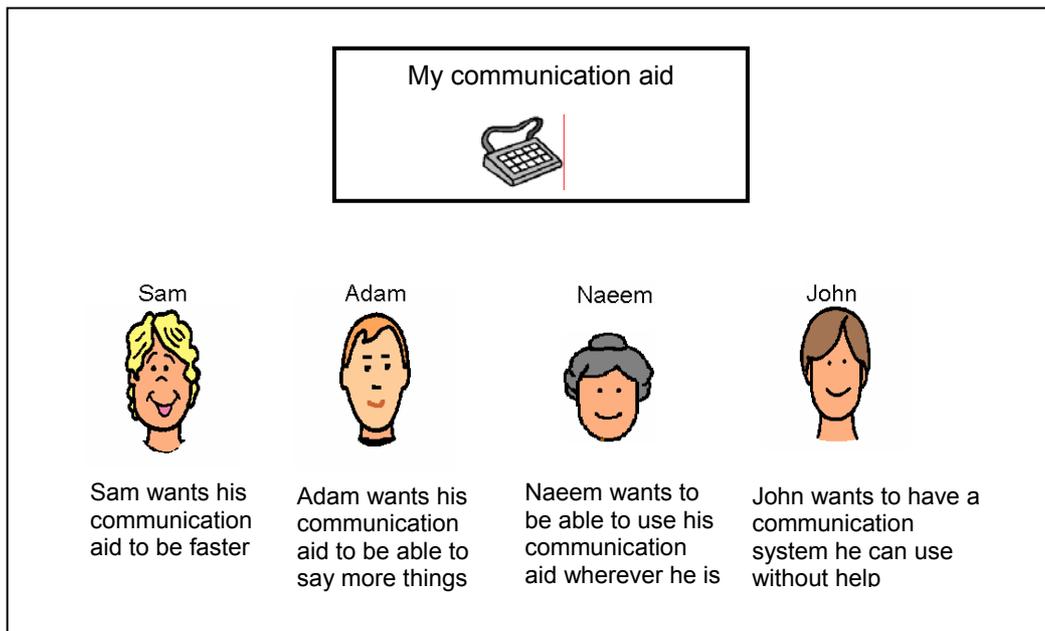
My communication aid

Sam

Sam wants his communication aid to be faster

Adam

Adam wants his communication aid to be able to say more things

Naeem

Naeem wants to be able to use his communication aid wherever he is

John

John wants to have a communication system he can use without help

DEVELOPING AN APPROACH TO INVOLVING CHILDREN WITH AUTISTIC SPECTRUM

DISORDERS IN A SOCIAL CARE RESEARCH PROJECT

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SUMMARY

A project researching user-views on the outcomes of social care and support services for disabled children and their families presented new challenges to a research team. While the team had experience of working with other groups of disabled children, this project was the first in which the team sought to work directly with children with autistic spectrum disorders. This paper reports the process by which the research design and methods used were developed and tailored to the needs and abilities of these children. The key lesson learnt was the value of crossing disciplines, research areas and professional boundaries when trying to identifying ways of working with a 'hard to reach group'.

INTRODUCTION

This paper reports the process by which a research approach was developed to support the inclusion of children and young people with autistic spectrum disorders[2] (ASD), in a social care research project. Children[3] with ASD do participate directly in certain areas of research such as work within the fields of psychology and education where, typically, their responses to specific stimuli or interventions are observed or measured. However, within social care research these children are a highly neglected group. Preece (2002) reports finding no published research which had included the direct participation of children with ASD. This runs counter to recent significant advances in the extent to which disabled children in general are directly participating in research regarding their care and welfare (for example, Stalker *et al.*, 2003; Watson *et al.*, 2000; Rabiee *et al.*, 2001; Morris, 1999). The key reason behind this discrepancy appears to lie in the nature of the condition. Autistic spectrum disorders are characterised by the so-called triad of impairments: impaired communication, difficulties with social interaction and a restricted range of interests and activities (Wing, 1993). Taken together these impairments present specific challenges to researchers wishing to consult children with this condition about their lives (Preece, 2002).

The research project in question was concerned with identifying the outcomes of social care and support services desired by disabled children and their families. Service outcomes are defined as the impact, effect or consequence of a service (Nocon and Qureshi, 1996), and work with older people and disabled adults has emphasised the need for a user-led approach to identifying the desired outcomes of services (Nocon, Qureshi and Thornton, 1997). Direct participation by disabled children was therefore one of the key aims of this project. However, while the research team had experience of working with other groups of disabled children, this project was the first to include direct work with children with ASD. This paper charts the team's experiences as they developed a research approach which would support the meaningful participation of these children and would allow the collection of as much information as possible about their desired outcomes. Thus this paper focuses very much on the development of an appropriate research design and methodologies. The findings of the research project are reported elsewhere (Beresford *et al.*, submitted).

The project focused on a four 'groups' of disabled children (0-17 yrs) who had either: complex health care needs, a degenerative condition, did not use speech to

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[2] The term 'autistic spectrum disorder' (ASD) indicates the fact there is considerable individual variation in the manifestation and severity of the cluster of impairments which characterise autism namely: impaired social interaction, impaired communication and restricted, stereotyped and repetitive patterns of behaviour, interests and activities, linked to a lack of imagination (World Health Organisation, 1992).

[3] For ease of reading, for the remainder of the paper the term 'children' is used to mean 'children and young people'.

communicate (for physical reasons), or an autistic spectrum disorder. The fieldwork with parents and non-autistic children involved semi-structured interviews (where appropriate using non-verbal methods) about all aspects of a child's life (for example, friendships, school, physical and mental health, transition to adulthood). Researchers explored achieved and desired outcomes (both for the present and the future) with respect to the different aspects of a child's life and also perceptions as to the role services might play in achieving these desired outcomes. What became very clear early on in the project was, that for the reasons outlined earlier, this approach would need to be revised for the work with children with ASD.

SEARCHING THE LITERATURE AND CONSULTATION

This process of revising the research approach began with a search of the social care literature. This revealed very little work in which children with ASD had been directly involved, and the search was therefore extended to other disciplines. Within education a sizeable body of research was identified, some of which included the direct involvement of children (for example, Potter and Whitaker, 2001), and the psychological research into ASD *per se* was very useful in terms of developing an understanding of the condition. However, the questions posed by the research project called for methods which would enable the researchers to access children's views on quite abstract concepts, such as their views about their lives and their desires and aspirations, and this differed to the sorts of questions being posed by psychological and educational research.

A key publication within social care research was Preece's work (2002). He noted the anomaly of a lack of research involving children with ASD despite the fact they were likely to be service users. Preece identified a number of ways in which features characteristic of ASD might impact on the research process. Those particularly pertinent to the project included: concrete thought processes, difficulties looking to the future, lack of personal insight and dislike of change. Together these meant that questions about their desires and aspirations may be meaningless and, possibly, threatening. In addition, any methods used needed to accommodate potentially high levels of social anxiety and the individualised way in which the disorder manifests itself.

Fortuitously, the team also encountered a report of a project involving very young children (sometimes pre-verbal) in evaluations of their day care (Clark and Moss, 2001). Entitled the Mosaic Approach, a range of methods (observation, drawing, interviews) and informants (child, parents, day care staff) had been used to build up a picture of an individual child's experience of their day care. Despite its origins within early years childcare research, the approach seemed to have potential for working with children with ASD.

At this stage the team also attended academic seminars and practitioner training days about working with children with ASD and more, generally, children and adults

with learning difficulties.   In addition, the team organised a multi-disciplinary seminar attended by both researchers and practitioners.   It proved extremely useful, allowing detailed (and honest!) discussion of previous research experiences. The practitioners provided valuable first hand knowledge of autistic children, and also shared the methods they used, in a practice context, to work with these children.

MOVING FORWARD

The 'product' of these preliminary activities was that the team was able to clarify the aims of their work with children with ASD, to develop a strategy for including these children in the project, and to make provision for the fact that, more so than other children, these children would be reluctant to participate. It was clear that the project needed to respond to the specific demands of working with these children not only in terms of developing appropriate methods but, more fundamentally, to revisit the research questions themselves and to consider whether, with respect to children with ASD, they were meaningful and appropriate. In addition, as well as obtaining parental views' on their desires and aspirations for their child, it would be important to be able to seek the views of others who would hold informed views about that child.

A 're-statement' of research aims

There was a concern among the research team that the work with the children with ASD might be seen as 'less successful' than other aspects of the project where it had been possible to explore, often in some depth, the views and aspirations held by other groups of disabled children, including those who did not, for physical reasons, use speech to communicate. It therefore seemed important, based on the findings from the preliminary stage described above, to make an explicit statement about the way the aims of the research needed to be 're-formulated' to accommodate the needs and abilities of the children with ASD. The aims and purpose with respect to the work with this group of children within the project were as follows:

1. To support direct participation, *wherever possible and however limited*, in the project by the children with ASD.
2. To 'pull in' the concept of outcomes to a concrete, here and now level; but where the child was able to provide opportunities to explore outcomes more abstractly and with a view to the future.
3. For participation by children in direct work to be an enjoyable, non-threatening experience, involving methods that can work with the child's interests and strengths and are flexible in terms of different abilities.
4. To learn from the experiences of seeking to facilitate the inclusion of children with ASD in the project.

Methods and sources of data

Research design

A research design was proposed which drew on a number of 'data sources' with reference to a particular child (this was informed by the Mosaic Approach identified

during the preliminary work). This included interviews with children, parents, and Other Informants (these would be nominated by parents as someone who knew the child well in a different setting), and informal observation of the child in the school setting. Each of these elements of the design are described below. The following section ('The Fieldwork') reports the team's experiences of implementing the design.

The 'interviews' with the children
Alleviating social anxiety and ensuring the questions asked of children were meaningful to them were key concerns. A number of strategies were incorporated to address these issues. These included:

- using Social Stories;
- using a familiar craft-making activity as the focus of the session;
- using photographs taken by the child;
- restricting the conversation to concrete, here and now experiences.

Social Stories were used to prepare the child for the visit from the researcher. Originating from the U.S. (Gray, 1994) Social Stories are used to help children with ASD understand and manage specific social situations. They are written for a specific child about a specific situation using a prescribed format which provides detailed, step-by-step information about why a situation is happening and what will happen (descriptive sentences) interspersed, less frequently, with sentences giving gentle advice about how to react (directive sentences). A Social Story was prepared for each child who was taking part in the project. An example of the text is given in Figure 1 below (photographs and illustrations were used to supplement the written information as indicated). The Social Stories were used by the parent a number of times before the researcher's visit. Two of the more able children received the social story directly, written in the form of a letter.

*** **Figure 1 in about here.**

The purpose of the Social Story was to inform and reassure the child about the researcher's visit. It did not address to issue of the child consenting to take part in the project. Written consent to interview a child was obtained from the parent, and parents received a project information leaflet and had a face to face meeting with a member of the research team prior to consent being sought. However, informed consent was not sought from the children themselves. As has been debated by other researchers working with younger children and those with learning disabilities, whether or not it is possible to truly obtain informed consent to participate in research is highly questionable (for example, Allmark, 2003). The research team was not confident that the children would understand the meaning and purposes of the research, or were competent to make a decision based on that information - both requirements for true informed consent (Beauchamp and Childress, 2001). Instead, therefore, an on-going process of assent was adopted. Thus the children's

responses to their parents talking to them about taking part in the project (including their reactions as they read through the Social Story) and their willingness to take photographs to be used during the research interview (see following section) were used as indicators of the child's willingness to meet with and talk to the researcher. Within the interview, any verbal or non-verbal indications that the child did not want the interview to continue were promptly acted upon by the researcher and the interview brought to a close.

A second strategy to alleviate social anxiety was to minimise direct, face-to-face interaction between the child and the researcher. This was achieved by basing the session around a craft activity which involving looking at photographs together and selecting ones to make a poster. Doing this shared activity also meant the researcher sat by, as opposed to opposite, the child. Anecdotal evidence suggested that, like all children, autistic children enjoy looking at photographs, and making a poster was similar to the sorts of projects many of the children did at school.

The need to adopt a concrete approach also supported the use of photographs taken by the child in the poster-making activity as opposed to generic pictures or symbols (which might have been mis-interpreted or been meaningless). A disposable camera was sent to the family prior to the interview and the child was encouraged to take photographs of the people, places and activities which were important to them.

In the 'interviews' with the children, any question posed as the poster was created focused on the 'here and now', with the aim of finding out what aspects of their lives the children viewed positively (with the inference being that this is something they want to keep as part of their lives) and those less positive aspects (possible areas for change). Though limited, this would provide data about outcomes the child had achieved and which were valued, or not. For some, it would also be possible to explore in more details the reasons behind likes and dislikes, and possibly, future desires and aspirations.

Interviews with parents and 'other informants'
The interviews with the parents and Other Informants followed a topic guide whereby views on desired outcomes for the child were explored (see Introduction). All the Other Informants were teachers and interviews with them took place in schools. These interviews were restricted to those areas of the child's life about which the informant knew and felt comfortable discussing. The interview also picked up on any issues specifically raised in the interview with the parent.

Informal observation
The interviews with the teachers (acting as Other Informants) often offered the opportunity to observe the child in school. The observation focused on areas arising from the parents' interviews about desired outcomes for their children. This included evidence of favoured activities, social interaction, opportunities to make choices and

to try new activities, and experiences of success. The observation also provided contextual data to teachers' and parents' accounts of a child.   Typically the observation took place during a half-day visit to the school. The researcher sat to one side in the classroom and did not initiate interaction with the children in the class or participate in any activities, though did respond if any child initiated contact.

THE FIELDWORK

Ethical approval to conduct the research was obtained from the Local Research Ethics Committee. Twenty-six families with a child with a diagnosis of autism or Asperger syndrome were recruited to the project. Within this sample, five children (aged between 6 and 14 years) were interviewed. Four children were diagnosed as autistic and one as having Asperger syndrome. All had statements of special educational needs, though none had severe learning difficulties. One child was in mainstream education, three attended special units and one went to a special school. For the remainder of the children represented in the project, data were collected from interviews with a parent (typically the mother) and, for all but three, from an 'Other Informant'. In all cases this was the child's teacher or headteacher. The majority of children were also observed in the classroom.

The number of interviews achieved with children themselves was disappointing, and there was a sense among the researchers that more children could have participated. The barrier to participation was parental unwillingness or an unwillingness, reputedly based on anxiety, of the young people themselves – especially those aged 12 years and above. Some parents felt their child's lack of insight meant the questions would not be meaningful to their child and they would not be able to respond. Others did not think their child would tolerate meeting someone new.   For some, the severity of their child's condition and associated learning and communication difficulties meant they felt that participation was impossible. Almost all parents were, however, pleased to suggest an 'Other Informant' and for the child to be observed at school. On reflection, the school environment might have been a more suitable environment for interviewing some of the children. Unlike home, school is a place where unfamiliar faces routinely appear and is not an unusual event. However, the nature of ASD means that some children would have found talking at school about their out-of-school lives difficult and confusing.

Where children did participate, parents reported that the Social Stories were a very helpful way of preparing the child. The photographs of the researcher and her car were something that the children really responded to, especially when they 'matched' what actually happened! In addition, the researcher (RT) who conducted the interviews was confident that the strategies used to ensure the children were assenting to participate worked and that none of the children participated or continued participation under duress.

Four out of the five interviews were successful in terms of being an enjoyable experience for the child and yielding relevant and valued data. The use of photographs and the poster-making activity worked well, and was effective in facilitating conversation while keeping social anxiety low. There was also a strong sense that, had it been possible, a repeat visit(s) would have allowed further exploration with the children about their lives. Two children were able to respond to more abstract questions about their likes and dislikes. All parents were surprised at how long the children spent with the researcher. The fifth interview was less productive as the child was not interested in taking part. This was not something the parent had envisaged and could have been for a number of reasons, such as the interview taking place soon after the child had returned from school.

Finally, the interviews with the Other Informants were extremely valuable, providing a different perspective to the parent's on desired outcomes for a child. One particular benefit of interviewing teachers was the wealth of experience many were able to draw on when discussing possible future outcomes for a specific child. This was something parents sometimes found very difficult, given that it is often unclear how the autism will 'develop' and the developmental levels and skills their child might eventually achieve. In addition, the chance to observe and sometimes meet a child who was represented in the project, but not directly participating, was appreciated by the researchers who, otherwise, would have had no contact with that child.

CONCLUDING COMMENTS
Providing sufficient methodological details to enable the replication of a piece of research is key to robust reporting of research. However, the process by which methods are developed and what did and did not work in the course of conducting fieldwork often remains hidden and unreported. It is difficult to publicise failures, or to share the struggles and setbacks encountered in the course of a research project. Yet it is very important that time is taken to consider and share the process by which methodological lessons are learnt. This is perhaps particularly the case when a new field of research is developing, as is happening within health and social care research, where the need to consult directly with the 'hardest to reach' users of services is increasingly being acknowledged (Minkes *et al.*, 1994; Morris, 2002).

The challenges faced by this particular research project stemmed from the way the nature of autism raised questions as to whether the basic aims and purpose of the project could be achieved. The research questions clearly needed to be revised so that participation by the children themselves, and the data collected, was meaningful. Once this issue had been addressed appropriate methods and ways of preparing the child to taking part in the research could then be developed.

There is a sense that the fieldwork ended before the full potential of the research design and methods had been fully explored. However, four key issues emerge from

the experiences reported above which have implications for the way research with disabled children, and not just those with autism, is carried out.

First is the importance of looking beyond one's own discipline or profession. There is a tendency, within academic circles at least, to limit reading and literature searching to a very narrow area, and often within a specific age group or developmental stage. Whilst this may be appropriate with respect to research findings, this is clearly not the case for research *methods*. An example here would be the way a research approach developed for pre-verbal toddlers to evaluate their childcare experiences informed the research design of this project.

Second, researchers should remember that health, education and social care practitioners possess a wealth of skills and methods of working with disabled children that might have the potential to transfer to research settings. Two key, and apparently successful, features of this project's methodology (the social stories and the poster-making activity) were 'transferred' from practice.

Third, it is important for researchers to be flexible and to be prepared to adapt and change aspects of a research project to accommodate the needs and abilities of those participating. Otherwise there is a danger that the nature of a research project itself becomes a barrier to participation by the population under research. What ended up happening in the project reported in this paper was that different research questions and methods were used with the children with ASD compared to the other groups of disabled children taking part. Taking this approach can feel like going against all that is taught about the qualities of 'good research', where consistency of method and research tools within a research project is advocated. However, there is a balance to strike between 'methodological rigour' and facilitating the direct participation in research by the groups who are the focus of the research. What is vital is that any changes or differences in approach are clearly reported and taken account of in the way the data are analysed and reported.

Finally, and linked to the previous point, 'remoulding' the project and development of methods so as to be appropriate for the children with ASD required resources both in terms of time and finances. This has implications in terms of the way researchers plan, cost and schedule projects. There is also a need for research funders to recognise that developing an appropriate research design and methodologies may be necessary, and that it is a fundamental part of the research process requiring adequate time and funding.

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Figure 1: Example of Social Story text used in the project

> *Rosemary Visits Ben at Home*
>
> This is a photo of Rosemary. *[photo]*
> Mum and Dad have met Rosemary at home when Ben was at school.
> Rosemary is coming to see Ben on Wednesday in the morning.
> She will come in her car – a red Polo. *[photo]*
> Rosemary will ask Ben some questions.
> She will ask about Ben's favourite things at school and at home.
> Rosemary will ask about the people Ben knows.
> Rosemary and Ben will make a poster together about Ben. *[illustration]*
> They will make the poster with photos and drawings.
> Rosemary will bring a 'Stop' card with her. *[illustration]*
> Ben can hold to Stop card up to stop or have a break.
> Rosemary will be at Ben's house for about an hour.
> Then she will go and it will be lunchtime. *[illustration]*

APPENDIX FIVE

Sample Information Sheets for Evaluation

PILOTING THE NEW FORM: 'WHAT CHILDREN AND FAMILIES WANT TO ACHIEVE'
Does it work? Is it helpful? What would make it better?

EVALUATION PHASE

INFORMATION SHEET FOR STAFF

The development project
A multi-agency group of staff in Bradford have been working on a development project with the Social Policy Research Unit, University of York. The project has been developing a tool by which desired outcomes for disabled children and their families can be assessed. The tool has been based on research with families with children with complex health care needs and/or communication impairment.

Evaluating the pilot
You have been involved in piloting this tool with parents. In order to evaluate the tool we are talking to children, parents and staff who have used the tool. We would like to talk to you about your views and experiences of using the tool. We would arrange a mutually convenient time to come to interview you. The interview would last no longer than an hour. We would like to tape-record the interview. The tape-recording will only be listened to by the research team and will be stored securely. It will be destroyed at the end of the project.

Your rights
If you agree to be interviewed it is important you know that you do not have to answer any question you do not want to, and that you can terminate the interview at any stage. It is also quite acceptable for you to choose not to participate. The decision you make is confidential between yourself and the research team.

Reporting on the pilot
We will be writing a report about what we find out. It will not be possible in the report to identify anyone who took part in project. You will receive a copy of the report.

Our contact details
The lead researcher for this project is Parvaneh Rabiee (pr15@york.ac.uk). You can contact Parvaneh with queries about the project but she will not be carrying out the evaluation interviews. These need to be conducted by a researcher who has not been involved in the project. As a result, Veronica Greco (vg3@york.ac.uk) will be conducting the interviews with children, parents and staff. Veronica and Parvaneh can be contacted on 01904-321950 and their postal address is Social Policy Research Unit, University of York, Heslington, York YO10 5DD.

THE UNIVERSITY *of York*

S | P | R | U

Evaluating the new form: 'What children and families want to achieve' consent form for staff

This form is to make sure that we have explained everything that is involved in the research project to your satisfaction, and for you to state whether or not you agree to take part.

Have you read the information sheet about the project and do you feel you understand what taking part in the project involves? **Yes/No**

Have you talked to the project worker about the project? **Yes/No**

Do you know that you are free to withdraw from the study at any time, and without giving a reason? **Yes/No**

Do you know that all the information from the research will be kept strictly private and confidential? **Yes/No**

Do you agree that the information from the research can be published if your identity is kept secret? **Yes/No**

Would you like to take part in the evaluation of the new parental well-being assessment? **Yes/No**

Do you agree to the interview being tape-recorded? **Yes/No**

Signed…………………………………….

Name……………………………………   **Date …………………………..**

Signature of researcher ………………………………………….

Name …………………………………………………………….

RESEARCH PROJECT

**The new form: 'What children and families want to achieve'
Does it work? Is it helpful? What would make it better?**

INFORMATION SHEET FOR PARENTS

What's this about?
- Services in Bradford want to get better at supporting disabled children who have complex health care needs and children who do not use speech to communicate and their parents.

- They are trying out a new way of finding out what children and parents want to be able to do and achieve, and how services can best help them. The new form they are using is called: 'What children and families want to achieve'.

Who am I?
- I am a researcher from the Social Policy Research Unit at the University of York. My name is Veronica Greco.

- You can contact me on: 01904-321950; or email: vg3@york.ac.uk. My postal address is: Social Policy Research Unit, University of York, Heslington, York YO10 5DD.

What have we been asked to do?
- We have been asked to find out what children, parents and staff think about the new form and how it is working.
- In order to do this we would like to talk to parents about their assessment and to have a copy of the completed assessment forms. These would be treated with the strictest confidence.
- We will be writing a report about what we find out. It will not be possible in the report to identify anyone who took part in project.

What does taking part in the project involve?
- Taking part in the project would involve a short, confidential interview with a member of the research team at a time and place convenient to you. We would also ask you to agree that a copy of your form is passed on to us. We would like to tape-record the interview. The tape-recording will only be listened to by the research team and will be stored securely. It will be destroyed at the end of the project.

- If you take part, it is OK to choose not to answer questions we ask you or halt the interview at any stage. If you do this, it will not affect the services or other support you receive.

- If you are happy to take part please complete the form below and return it to us using the reply paid envelope.

- It is OK if you don't want to take part, it will not affect the services or other support you receive.

THE UNIVERSITY *of York*   S|P|R|U

Evaluating the new form: 'What children and families want to achieve' consent form for parents

This form is to make sure that we have explained everything that is involved in the research project to your satisfaction, and for you to state whether or not you agree to take part.

Have you read the information sheet about the project and do
you feel you understand what taking part in the project involves?   **Yes/No**

Have you talked to one of the project workers about the project?   **Yes/No**

Do you know that you are free to withdraw from the study at any time,
and without giving a reason?   **Yes/No**

Do you know that all the information from the research will be kept
strictly private and confidential?   **Yes/No**

Do you agree that the information from the research can be published
if your identity is kept secret?   **Yes/No**

**Would you like to take part in the evaluation of the new form:
'What children and families want to achieve'**

Yes/No

Do you agree to the interview being tape-recorded?   **Yes/No**

Signed……………………………………….

Name………………………………………   Date …………………………..

Signature of researcher ……………………………………………….

Name ………………………………………………………………………

APPENDIX SIX

Topic Guides for Evaluation of Pilot Phase

**WHAT CHILDREN AND PARENTS WANT TO ACHIEVE: ASSESSMENT TOOL
EVALUATION OF PILOTING OF OUTCOMES FOCUSED TOOL**

PARENT'S VIEWS AND EXPERIENCES: TOPIC GUIDE

PRIOR TO THE INTERVIEW, ESTABLISH:
How much time she/he has for the interview
Informed consent – sign the form
Tape recording
Confidentiality

BASIC INFORMATION
1. Who completed the form with you? [Member of staff's name]

2. Did you get a chance to look at the form beforehand?

3. Did you receive the information sheet before hand? (Show copy of the information sheet)

4. Did you complete the form during one session or over a number of visits?

5. Do you have your own copy of the completed form?

6. Do you feel it is a good/bad record of your discussion at the assessment?

VIEWS OF THE FORM

7. There were two sections: Desired outcomes for the child and desired outcomes for parents/carers. Did you complete both sections?

For each section completed ask the following questions:
8. Looking now at the different areas/bits of each section ……

- a. Thinking about and describing that area of your child's life/your life, and whether you wanted to make changes
  - How easy/difficult did you find it to think and talk about this?
    - o Possible probes: Why do you think that? Was there anything your worker did/said which helped you to think about this? Can you give me an example?

- b. Setting goals
  - How easy/difficult was it to identify goals?
  - How easy/difficult was it to rate/prioritise the goals for the child?
  - Did you find rating/prioritising the goals for the child useful?
    - o Possible probes: Why do you think that? Was there anything your worker did/said which helped you to think about this? Can you give me an example?

- c. Summary and actions
  - How did you and your worker go about filling in this section?
    - o Possible probes: Did the worker direct things, make suggestions?
    - o *Did you and your worker think about actions that you could do yourself which did not require support or input from services?*

d. Overall, did you find it helpful to complete this section?
   - o Possible probes: Has it affected how you view your child's/your situation? Has it resulted in anything happening/changes to this area of your child's/your life?

e. Any criticism/suggestions for improvement to the form?
   - o Possible probes: Do you think the forms are/are not 'user- friendly'?

(Repeat this section for all the areas/sections completed)
For sections which were not completed

9. I notice that you did not complete XXX section. Could you tell me why that was?
   - o Possible probes: Parents vs workers choice and reasons why. Might need to go carefully here (e.g. if not completed 'emotional well-being section')

OVERALL VIEWS AND EXPERIENCES

10. Do you feel you had sufficient information about the form and the process of completing it before attempting to complete it?
   - o Possible probes: Did you find the information sheet useful? Was there anything your worker did/said which helped you to understand what was happening?

11. Overall, having completed this assessment what did you find particularly useful/not useful?
   - o Possible probes: Identification of specific aims for your child, identification of aims for yourself, prioritising aims, recording actions……

12. Were child's views accessed? If so, how?
   - o Possible probes: Did you find it useful/helpful or not? If yes, in what way? If not, what was the problem?
   - o If child's views not obtained – why not?

13. *Ask parent to nominate one particular good/useful thing, one particular bad/unhelpful thing about the form and/or the process of completing it.*

14. When you were completing the form with your worker, did you just think about things that services could help you achieve or did you think more widely than that?

15. How could it be improved?
   - o *Probe: timing of completion, information about the assessment, how the worker went about it, dealing with sensitive issues, areas covered…….*

16. Do you think the form provided helpful/useful information about you for your worker?
   - o Probe: how was it useful for the worker?

17. Do you feel that identifying specific goals for your child and yourself as a parent means you are less or more likely to achieve your outcomes (goals)?
- o   Probe: Why is that?

18. What has happened since you completed the assessment? Do you feel you are any nearer to achieving outcomes you identified? If so, why/how? If not, why not?

19. How did you find thinking about outcomes or changes you wanted to achieve in the different areas of your life/child's life? Was it difficult, useful, helpful/unhelpful etc.?

OTHER ASSESSMENT EXPERIENCES

20. Have you had other assessments for your child or yourself as a parent of a disabled child?

21. If yes, do you remember what those assessments were for/what they were called? Was this assessment different in any way to other assessments?
- o   Probe: issues covered, type of information recorded, beliefs re usefulness etc., views on which was better/more useful for the child/for parent.

22. Is there anything else you would like to add?

Thank you for taking part in this interview. Ask if a follow up telephone call some time later is possible.

WHAT CHILDREN AND PARENTS WANT TO ACHIEVE: ASSESSMENT TOOL
EVALUATION OF PILOTING OF OUTCOMES FOCUSED TOOL

STAFF VIEWS AND EXPERIENCES: TOPIC GUIDE

PRIOR TO THE INTERVIEW:

1.   Establish how much time the staff member has.
2.   Confidentiality – management will only receive general views, not attributed, etc.

BACKGROUND INFORMATION

1.   What post do you hold?
2.   Length of service.
3.   How many families have you used the tool with?
4.   How many children did you involve directly?
5.   Did you use the tool as part of the initial/core assessment process or to re-assess children using short term care services?

EXPECTATIONS

6.   What were your views about the tool before you started using it?
  ➤ *Possible probes:*
    o *useful/helpful or not;*
    o *A different approach to usual way of working vs similar approach*
    o *Compatible with usual way of working vs incompatible?*

7.   Did you envisage any problems with using the tool?

OUTCOMES TRAINING

8.   Did you attend the training workshop about the tool in December? What were your views about it?
  ➤ Possible probes:
    o *How useful was the training;*
    o *How confident were you after the training about:*
      • *Adopting an outcomes focus*
      • *Using the new documentation*
    o *Did you find the written guidance notes about how to use the tool sufficient?*
    o *Do you have any suggestions for other training/input?*

USE OF THE TOOL

9.   How have you gone about using the tool?
  ➤ *Possible probes:*
    o *When used the tool with a family? (in terms of overall contact with family e.g. first visit, or later on in work with family etc..)*
    o *Form was discussed and completed as went along vs form left with family and discussed and completed later on?*
    o *Completed in one session vs completed over a number of sessions?*

10. Were there any other agencies (egg education, health) involved in the piloting of the tool? How did it work?
    ➢ Possible probes:
        o *Did you find it useful/helpful or not?*
        o *If yes, in what way?*
        o *If not, what was the problem?*

11. Were there any sections you left out?
    ➢ *Possible probes*
        o *Not relevant- worker and parent*
        o *Difficult to understand- for child, for parent*

12. If you have used the tool a number of times have you changed or varied the way you used it? If yes, what were those changes, and what were the reasons for those changes?
    ➢ Possible probes
        o Changing the order in which completed the form

VIEWS ABOUT THE TOOL

13. Earlier you told me how you felt about the tool before you used it. Now you have used the tool, what are your views about it?
    ➢ *Possible probes*
        o *Better or worse than you expected*
        o *Unexpected benefits*
        o *Unexpected problems*

14. Did you experience any difficulties in getting parents to think about themselves as opposed to their child?
    ➢ Possible probes
        o Did the form help or make this more difficult
        o Did parents find some sections/areas of their life easier than others?

15. Did you have any concerns about broaching certain topics/issues with a parent/parents? If yes, what did you do?

16. Did you use the tool to access child's views? If so, how?
        o Possible probes: Did you find it useful/helpful or not? If yes, in what way? If not, what was the problem?
        o If child's views not obtained – why not?
            ▪ probe – communication skills, time, resources

17. What do you think are the most valuable aspects of the tool? (Look through the tool together, point out the various sections)
    ➢ *Possible probes*
        o *Valuable for worker*
        o *Valuable for child*
        o *Valuable for parent*
        o *Valuable for management of the case*

18. What aspects of the tool don't work well?
    ➢ *Possible probes*
        o *Don't work well for worker*
        o *Don't work well for child*
        o *Don't work well for parents*

- o *Don't work well in particular situations*
- o *Don't work well re management of the case*

19. Do you think the tool helped you and parents to identify solutions/actions which were not a service? If yes, can you give me an example(s)?

20. Do you think the tool changed (or had the potential to change) the way you work with families?
    - ➢ *Possible probes:*
        - o *If yes, ask for examples*
        - o *If no, why not*

21. Do you feel parents and children responded positively or negatively to the tool?

22. How do you compare the tool with the previous assessment tools?
    - ➢ Possible probes:
        - o *The work is more or less targeted on the service user's personal goals*
        - o *The service user understands more or less about the purpose of intervention*
        - o *Lead to the same or different types of services being provided*

23. We have been piloting this tool among children with complex health care needs and children who do not use speech to communicate and their parents. Do you think it could be used with other groups of children/parents and in other settings?
    - ➢ *Possible probes*
        - o *types of condition*
        - o *types of setting*

24. This tool included thinking about outcomes for parents. Is this something you covered in your contacts with parents before this project? If yes, in what way?

25. What are your views about taking an outcomes approach?
    - ➢ Possible probes
        - o Useful or not – worker and parent
        - o Advantages and disadvantages – to worker and to parent
        - o Informing service development?

FUTURE USE OF THE TOOL

26. At the moment the tool is part of a research and development project and you have been involved in piloting it. Do you think you will continue to use the tool after the pilot study?
    - ➢ *Possible probes*
        - o *If yes, ways in which will use it. Any barriers to continue using it? Views on how those barriers might be overcome.*
        - o *If no, why not.*

27. Do you think the tool should be adopted by your agency/department and used routinely?
    - ➢ *Possible probes*
        - o *If yes, perceived benefits, barriers to that happening.*
        - o *If no, why not*

28. Is there anything you would like to add?

Thank you etc...

APPENDIX SEVEN

Papers Reporting the Research Findings

Copyright restrictions do not allow us to disseminate these articles ourselves. Please see the spru website for full bibliographic references to the articles:

http://www.york.ac.uk/inst/spru/research/summs/priorpercep.htm

APPENDIX EIGHT

Tools Developed in the Development Work

AREA A

Tool
Guidance notes for staff
Information sheet for parents

PARENTAL WELL-BEING

MULTI-AGENCY OUTCOMES FOCUSED TOOL FOR ASSESSMENT AND REVIEW

Parent's name:
Address:
Telephone number:
ID number:
Religion:
Name(s) of child/children with diagnosis of ASD:
Ethnicity/culture:
Communication/access requirements:
Completed by: *Name:*   *Agency:*   *Address:*   *Phone/e/mail:*
Date:
Date of referral:
Source of referral:
Summary of parent's situation

WORKERS INVOLVED WITH THE FAMILY (NAME, JOB TITLE, ORGANISATION)

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

11.

SHARING INFORMATION WITH OTHER SERVICES

- People working in health, education, social services and voluntary organisations are all using this form to assess parental well-being.

- During your assessment something might come up that the worker cannot help you with.

- However, it may be that a different worker or service could help you. In these situations we would like to be able to share the information collected on this form with other workers or services.

- We need you to agree to us sharing that information with other professionals and/or services.

- Please read the following.   If you agree with them please sign in the space provided.

   ➢ **I have read and understand the above statements.**

   ➢ **I understand that information collected as part of this assessment may be shared with other professionals or workers. This will only take place in order to better to support me and/or my family.**

   Signed: _____

   Name: _____

   Date: _____

Other comments or issues that arose during the assessment and cannot be recorded in the following sections can be noted here.

PHYSICAL WELL-BEING

Parents tell us things like **tiredness** due to lack of sleep. Interrupted sleep and the demanding nature of day to day life can affect their physical health. There can also be **physical symptoms** of stress such as tension, headaches, stomach upsets etc..

Is this an area of your life that you want to change or improve?
(If yes, provide a brief description of the current situation)

How important is it to make a change in this area of your life? ____   [___ ___ ____ ___]
(High, Medium or Low priority)   *[For use at reviews/evaluation]*

What would be your aim?

    Aim: _____ *Priority:* ____

       Use this rating scale to show where you are now:

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

Specialist services may wish to identify more than one aim.

    Aim: _____ *Priority:* ____

  Use this rating scale to show where you are now:

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

    Aim: _____ *Priority:* ____

  Use this rating scale to show where you are now:

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

    Aim: _____ *Priority:* ____

  Use this rating scale to show where you are now:

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

SUMMARY AND ACTIONS: PHYSICAL WELL-BEING

Aim (These can be split into 'sub-aims'.)	What will be done?	Who will do it & by when?

REVIEWS OR THE END OF USING A SERVICE: PHYSICAL WELL-BEING

4. *Have a look at what you and your worker wrote down when the assessment was carried out.*
5. *How important is it to you NOW to make changes to this area of your life?*
6. *Thinking about your aim(s), where are you at now? Show this on the rating scale(s).*

What do you think most made this change(s) (good or bad) happen?

Are there any new issues or aims that have emerged since the assessment or review?
(If yes, provide a brief description of the changes.)

New aims arising from reviews.

Aim: _____ *Priority:* _____

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

Aim: _____ *Priority:* _____

Use this rating scale to show where you are now:

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

FEELING SKILLED AND INFORMED

o **Feeling you know best how to** …. deal with difficult behaviours and situations; help your child to learn; help you child to enjoy him/herself; understand and meet your child's needs.

o **Feeling that you know** … everything you need to know about your child's condition and the services (local and national support services (voluntary and statutory), statutory benefits and other sources of financial support) that are available to help your child and your family.

Is this an area of your life that you want to change or improve?
(If yes, provide a brief description of the current situation)

How important is it to make a change in this area of your life? ____   [___   ___   ____   ___]
*(**H**igh, **M**edium or **L**ow priority)*   *[For use at reviews/evaluation]*

What would be your aim?

> *Aim:* _____ *Priority:* ____

> *Use this rating scale to show where you are now:*

> | Very far from my aim | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | I have achieved my aim |

Specialist services may wish to identify more than one aim.

> *Aim:* _____ *Priority:* ____

> *Use this rating scale to show where you are now:*

> | Very far from my aim | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | I have achieved my aim |

> *Aim:* _____ *Priority:* ____

> *Use this rating scale to show where you are now:*

> | Very far from my aim | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | I have achieved my aim |

> *Aim:* _____ *Priority:* ____

> *Use this rating scale to show where you are now:*

> | Very far from my aim | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | I have achieved my aim |

SUMMARY AND ACTIONS: FEELING SKILLED AND INFORMED

Aim (These can be split into 'sub-aims'.)	What will be done?	Who will do it & by when?

REVIEWS OR THE END OF USING A SERVICE: FEELING SKILLED & INFORMED

1. *Have a look at what you and your worker wrote down when the assessment was carried out.*
2. *How important is it to you NOW to make changes to this area of your life?*
3. *Thinking about your aim(s), where are you at now? Show this on the rating scale(s).*

What do you think most made this change(s) (good or bad) happen?

Are there any new issues or aims that have emerged since the assessment or review?
(*If yes, provide a brief description of the changes.*)

New aims arising from reviews.

Aim: _____   *Priority:* ____

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

Aim: _____   *Priority:* ____

Use this rating scale to show where you are now:

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

EMOTIONAL WELL-BEING

Lots of different things can affect your emotional well-being:

o **coming to terms with** the diagnosis and coming to terms with/dealing with on-going events (e.g. changes in your child or the condition, lack of progress etc.);

o **having someone to talk to**/turn to (emotional support);

o having space/**time out** from parenting or caring;

o **feeling more than** just your child's parent or carer

Is this an area of your life that you want to change or improve?
(If yes, provide a brief description of the current situation)

How important is it to make a change in this area of your life? ____ [___ ___ ___ ___]
(High, Medium or Low priority)   *[For use at reviews/evaluation]*

What would be your aim?

> **Aim:** _____ *Priority:* ____
>
> *Use this rating scale to show where you are now:*
>
> | Very far from my aim | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | I have achieved my aim |
> |---|---|---|---|---|---|---|---|---|---|---|---|

Specialist services may wish to identify more than one aim.

> **Aim:** _____ *Priority:* ____
>
> *Use this rating scale to show where you are now:*
>
> | Very far from my aim | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | I have achieved my aim |
> |---|---|---|---|---|---|---|---|---|---|---|---|

> **Aim:** _____ *Priority:* ____
>
> *Use this rating scale to show where you are now:*
>
> | Very far from my aim | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | I have achieved my aim |
> |---|---|---|---|---|---|---|---|---|---|---|---|

> **Aim:** _____ *Priority:* ____
>
> *Use this rating scale to show where you are now:*
>
> | Very far from my aim | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | I have achieved my aim |
> |---|---|---|---|---|---|---|---|---|---|---|---|

SUMMARY AND ACTIONS: EMOTIONAL WELL-BEING

Aim (These can be split into 'sub-aims'.)	What will be done?	Who will do it & by when?

REVIEWS OR THE END OF USING A SERVICE: EMOTIONAL WELL-BEING

1. Have a look at what you and your worker wrote down when the assessment was carried out.
2. How important is it to you NOW to make changes to this area of your life?
3. Thinking about your aim(s), where are you at now? Show this on the rating scale(s).

What do you think most made this change(s) (good or bad) happen?

Are there any new issues or aims that have emerged since the assessment or review?
(If yes, provide a brief description of the changes.)

New aims arising from reviews.

Aim: _____ *Priority:* _____

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

Aim: _____ *Priority:* _____

Use this rating scale to show where you are now:

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

HOW SERVICES MAKE ME FEEL

Parents want services to make them feel....

o **confident** in the quality of services their child is receiving;
o that they are sharing **the responsibility** of meeting their child's needs;
o that they are working with professionals to do the best for their child and there are shared goals;
o that they are **being listened to** and **believed**;
o that they are **involved in decision-making**;
o that they are **not "a nuisance"**.

Is this an area of your life that you want to change or improve?
(If yes, provide a brief description of the current situation)

How important is it to make a change in this area of your life? _____   [____ ____ ____ ____]
*(**H**igh, **M**edium or **L**ow priority)*   *[For use at reviews/evaluation]*

What would be your aim?

Aim: _____ *Priority:* _____

Use this rating scale to show where you are now:

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

Specialist services may wish to identify more than one aim.

Aim: _____ *Priority:* _____

Use this rating scale to show where you are now:

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

Aim: _____ *Priority:* _____

Use this rating scale to show where you are now:

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

Aim: _____ *Priority:* _____

Use this rating scale to show where you are now:

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

SUMMARY AND ACTIONS: HOW SERVICES MAKE ME FEEL

Aim (These can be split into 'sub-aims'.)	What will be done?	Who will do it & by when?

REVIEWS OR THE END OF USING A SERVICE: HOW SERVICES MAKE ME FEEL

1. *Have a look at what you and your worker wrote down when the assessment was carried out.*
2. *How important is it to you NOW to make changes to this area of your life?*
3. *Thinking about your aim(s), where are you at now? Show this on the rating scale(s).*

What do you think most made this change(s) (good or bad) happen?

Are there any new issues or aims that have emerged since the assessment or review?
(If yes, provide a brief description of the changes.)

New aims arising from reviews.

Aim: _____   *Priority:* ____

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

Aim: _____   *Priority:* ____

Use this rating scale to show where you are now:

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

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PARENTAL WELL-BEING
MULTI-AGENCY OUTCOMES FOCUSED TOOL FOR
ASSESSMENT & REVIEW
```

GUIDANCE NOTES FOR WORKERS

1.   BACKGROUND INFORMATION

What do you mean by parental well-being?

This tool divides parental well-being into four areas. This is based on research with parents. The four areas are:

- emotional well-being;
- feeling skilled and informed;
- physical well-being;
- how services make me feel.

What is this tool for?

The purposes of this tool are:

- to facilitate a discussion with a parent about their well being;
- to help parents to think about different aspects of their well-being
- to identify changes they would like to see with respect to their well-being;
- to record the extent to which changes or improvements are achieved.

The tool can be used in a number of ways:

- for individual assessments and reviews, both general, broad brush assessments and more detailed service specific;
- to evaluate a service both for individual users and at a service level;
- to inform changes in service provision and service developments

What sort of information will I collect if I use it?

The tool records:

- parents' desired aims (outcomes) for the different areas of their well-being.
- on-going progress or change and the outcomes of using a service in relation to these aims.

Who can use the tool?

This tool has been designed so that it can be used by staff working for different agencies and providing different sorts of services. As a result not all sections will always be relevant.

2. USING THE TOOL

This tool has been designed such that it is completed alongside the parent. It is not a self-completion questionnaire.

This tool has been designed so that it can be used by staff working for different agencies and providing different sorts of services. As a result not all sections will always be relevant.

The assessment

The parent is provided with information about the assessment including the areas to be covered and the purpose of the assessment [see Parents' Information leaflet]. Parents are encouraged to begin to think about areas of their lives they might want to change and possible aims. It is important that the aims identified are specific, measurable, achievable/ realistic (though not limited to current service provision) and time-limited. Depending on the service that time frame will vary (is. short-term specific intervention vs medium term on-going support). The assessment takes place with the parent and worker using this form as tool to facilitate a discussion about the parent's well-being.

1. Background information is recorded on the first two pages. At the bottom of the second page there is a consent to share information form. **This only needs to be completed if one of the actions arising from the assessment is referral to another agency.**

2. For each area of well-being:
   - A brief description of the parent's situation is recorded and the parent rates how important it is to make a change in that area of their life (H=high, M=Medium, L=low priority).
   - Through discussion a realistic aim is identified and noted down. If appropriate a number of aims might be identified.
   - If a number of aims are identified, they can be prioritised (H=high, M=medium, L=low).
   - For each aim, the parent rates where they are now.
   - The 'summary and action' section is also completed. Again this is completed in discussion with the parent. In some cases the action may be referring on to another service. 'Actions' can include things the parent will do themselves.

At reviews and/or end of service

1. During a review or at the end of using a service, the parent records where they are at with respect to their aims using the rating scale. It is important to identify when different ratings were made (for example, make a note of the date by a circle, or use different colour pens).

2. Record the parent's views as to why things have changed.

3. Note any new issues or aims that have emerged and, if appropriate, record new aims.

' PARENTAL WELL-BEING ' ASSESSMENT

Information sheet for parents

"No-one has ever asked me what I needed."
(Parent of a child with an autistic spectrum disorder)

❖ Services in Leicestershire want to get better at supporting parents who have a child with an autistic spectrum disorder.

❖ They are trying a new way of assessing parent's well-being. This sheet gives you some information about that assessment.

❖ Listed below are the different areas of well-being which may be covered in the assessment.

> **Emotional well-being**
  Lots of different things can affect your emotional well-being, such as:
    ▪ coming to terms with the diagnosis and dealing with on-going events (e.g. changes in your child or the condition, lack of progress etc.);
    ▪ having someone to talk to/turn to (emotional support);
    ▪ having space/time out from parenting or caring;
    ▪ feeling more than just your child's parent or carer

> **Feeling skilled and informed**
    ▪ Feeling you know best how to …. deal with difficult behaviours and situations; help your child to learn; help you child to enjoy him/herself; understand and meet your child's needs.
    ▪ Feeling that you know … everything you need to know about your child's condition and the services that are available to help your child and your family.

> **Physical well-being**
  Parents tell us things like tiredness due to lack of sleep. Interrupted sleep and the demanding nature of day to day life can affect their physical health. There can also be physical symptoms of stress such as tension, headaches, stomach upsets etc..

> **How services make me feel**
  Parents want services to make them feel….
    ▪ confident in the quality of services their child is receiving;
    ▪ that they are sharing the responsibility of meeting their child's needs;
    ▪ that they are being listened to and believed;
    ▪ that they are involved in decision-making.

❖ **An important part of the assessment will be to talk about whether there are changes you want to make in these areas of your life.**

❖ **If you do want to make changes, you and your worker will think together about the aims you might have for that area of your life, and how services can help you achieve those aims.**

AREA B

Tool
Guidance notes for staff
Information sheet for parents

What children and parents want to achieve
By outcomes we mean what the child and their parents want to achieve through service provision

1. DESIRED OUTCOMES FOR THE CHILD

Health and well-being:	Description	
	Is there anything in this area of the child's life that the child or parents want to change or improve? What are the good or valued things in this area of the child's life, which they would want to maintain?	
	Parent's views	*Child's views*
Physical health and functioning *Note: Children's potential for physical health and functioning may vary. While for some children this would refer to preventing or minimising deterioration for others this might be about making improvements in the child's health and functioning.*		
Physical comfort / not being in pain *Note: Feeling comfortable and not being in pain is an important aspect of some children's health. Lots of things can affect this, such as the child's medical condition, the equipment they use or the way they are handled.*		
Feelings and emotions Note: Lots of things can affect the child's mental/emotional well being, such as, coming to terms with their condition and/or treatment, feeling left out.		
Safety and access:	**Description (as above)**	
	Parent's views	***Child's views***
Feeling safe and secure ***Note: This refers to child's safety and protection when they are looked after by non-family members.***		

Physical environment (inside and outside home) _Note: Moving about in their homes and other places they spend time can be very difficult for some children. For some, parts of their home/garden can be unsafe. Difficulties with public transport mean that some children cannot use it or do not feel safe using it._		
Moving about by myself Note: This is about moving about independently, at home, school, local community or other places the child spends time.		
Communication:	**Description (as above)**	
	Parent's views	_Child's views_
Being able to communicate _Note: For some this could be the ability to understand and express simple concepts such as 'yes' and 'no'. For others this could be acquiring more advanced skills and/or having the right communication equipment in all the places they need it._		
Understanding others and being understood _Note: This is about children's experiences of being in situations where people (children/adults) do not understand the way they communicate, or where they do not understand other people's communication._		
Social relationships and leisure:	**Description (as above)**	
	Parent's views	_Child's views_

Friendship *Note: This could include having friends and the opportunities to see friends.*		
Activities and leisure time *Note: This could include opportunities to be stimulated, meet people, and experience different activities in different environments.*		
Family relationships *Note: Most children want to have opportunities to sustain good family relationships. This could include relationships with parents, siblings and members of extended family.*		
Education and learning	**Description (as above)**	
	Parent's views	*Child's views*
Self care and life skills Note: Children have different learning potential. Self care skills could include being able to feed, use the toilet and wash more independently, etc. Life skills could include being able to make snacks and understand the value of money and managing it, etc.		
Educational achievement Note: Children have different learning potential. This could range from having basic reading/writing skills to more advanced achievements leading to future employment.		
Other new skills **Note: Children may want to learn other skills, which are not taught at school (such as sport, dancing, music)**		

Identity, social presentation and participation	Description (as above)	
	Parent's views	*Child's views*
How people treat the child Note: This includes such things as being treated with dignity and respect, not underestimating the child's ability, and recognising their success and achievement.		
Appearance and personal hygiene Note: Appearance (including the clothes they wear and the equipment they use) as well as personal hygiene can affect how children feel about themselves.		
Opportunities to make choices and be involved in decisions Note: Making choices ranges from everyday decisions such as what to wear and eat, to how and where they spent their time, to planning for the future. children want to be properly included in consultations with the professionals, such as people talking to them rather than their parents.		

Summary of outcomes (goals) for child		Sub- outcomes (sub-goals) to be met	Who will assist the child to achieve each of these outcomes?	Priority (rate 1,2 or 3)
Parent's views				
Child's views				

2. DESIRED OUTCOMES FOR PARENTS/CARERS

	Description *Is there anything in this area of your life that you want to change or improve?*
Quality of life Note: Most parents want to have a life apart from being a parent/carer. There are different ways that parents want to achieve this, such as having time for self (time out from parenting/caring) and/or with partner, and opportunities to take up employment and other interests.	
Physical health and emotional well-being Note: Parents physical health and emotional well-being can be affected by their caring role. For example, back problem, exhaustion, stress, etc.	
Parenting Note: A lot of parents want to have opportunities to spend quality time (other than time spent on caring) with their disabled child/ren as well as non-disabled child/ren. Many also want to have opportunities for all family members to spend time together.	
Skills and knowledge in supporting the child's well-being Note: Feeling skilled and informed is a positive resource in supporting the child. It includes: knowing about child's condition; having skills to deal with difficult situations; how to maintain/maximise the child's health and functioning; and what services/resources are available to help child/family.	

Access to resources Note: Parents want to have access to adequate resources to help their child achieve desired outcomes. This includes such things as financial resources, suitable equipment and housing.	
How services make parent/s feel Note: Parents want to be involved in decision-making and to feel they share the responsibility of meeting their child's needs with professionals. They want to feel respected and valued by services and be confident in the quality of care their child is receiving.	

Summary of outcomes for parent/carer	Sub-outcomes to be met	Who will assist parent/carer to achieve each of these outcomes?	Priority (rate 1,2 or 3)

3. SUMMARY OF ASSESSOR

Assessor's signature: ……………………………………………………….. **Date:** ……………………………

Parent/carer's signature: ……………………………………………… Date: ………………………………

Parent/carer's signature: ……………………………………………… Date: ………………………………

Child's signature: ……………………………………………… Date: ………………………………

ACTION PLAN

Outcomes are the end results, goals and achievements of service provision

Action Plan for the child

OUTCOMES (GOALS) to be met for the child	**SUB- OUTCOMES (SUB GOALS)** to be met	**WHAT** will be done?	**WHO** will do it and **BY WHEN?**
1.			
2.			
3.			
4.			

Action Plan for the child's parent/s

OUTCOMES (GOALS) to be met For the child's parent	SUB-OUTCOMES (SUB GOALS) to be met	WHAT will be done?	WHO will do it and BY WHEN?
1.			1.
2.			
3.			
4.			

Review Plan

Review Plan for the child

OUTCOMES (GOALS) we said we would aim for	SUB-OUTCOMES (SUB GOALS) we said we would aim for	Has the outcome been achieved? (Yes/No/Ongoing)	If 'no' why not and what needs to be done now?	Action: who will do what and when?
1. 2. 3. 4.				

Reassessment of desired outcomes (identifying new or unmet desired outcomes)*

* NOTE: If several new desired outcomes are apparent, or substantial amendments are to be made to the care plan, a new outcomes focused Care Plan document should be used.

Review Plan for the child's parent/s

OUTCOMES (GOALS) we said we would aim for	SUB-OUTCOMES (SUB GOALS) we said we would aim for	Has the outcome been achieved? (Yes/No/Ongoing)	If 'no' why not and what needs to be done now?	Action: who will do what and when?
1. 2. 3. 4.				

Reassessment of desired outcomes (identifying new or unmet desired outcomes)*

* NOTE: If several new desired outcomes are apparent, or substantial amendments are to be made to the care plan, a new outcomes focused Care Plan document should be used.

The new outcomes focused forms

Guidance notes for workers

The guidance notes have been designed to clarify terms and to provide sources of assistance for professionals using the new outcomes focused forms.

These notes cover the new outcomes focused form called 'What children and parents want to achieve', Action Plan and the Review Plan.

What are outcomes (goals)?

Outcomes can best be thought of as the end product or goals the service user desires to achieve, that is the results or impact of a service rather than the provision of a service itself. Outcomes could refer to making improvements, preventing or minimising deterioration in any area of one's life. An example of a child's desired outcome relating to the area of social relationships and leisure would be having opportunities to meet people and experience different activities.

What are sub-outcomes (sub-goals)?

The sub-outcomes should be thought of as the contributory parts that go towards achieving the desired outcomes. These are best thought of as 'milestones' or 'building blocks' that go towards achieving the main outcomes. An example of a sub-outcome would be 'finger eating' as a step towards 'eating independently'.

What outcomes are the forms aiming to identify?

Research at SPRU identified desired outcomes for disabled children and their parents. These were identified by talking to children (or other informants if children were unable to participate directly) and their parents. The identified outcomes cover the following areas of child's life:

- Health and well-being
- Safety and access
- Communication
- Social relationships and leisure
- Education and learning
- Identity, social presentation and participation

The identified outcomes for parents cover the following areas:

- Quality of life
- Physical health and emotional well-being
- Parenting
- Skills and knowledge in supporting child's well-being
- Access to resources
- How services make parents feel

Using the form 'What children and families want to achieve':

1. Desired outcomes for the child: This section is divided into areas of the child's life listed above. It aims to identify outcomes the child wants to achieve as well as those his/her parents want the child to achieve through service provision. Each heading contains a description to help you understand what it is. The idea is to encourage a child and his/her parent/s to think about areas of the child's life they might want to change or maintain and possible aims. For some children this could be wanting to minimise deterioration in their condition. It is important that the aims identified are specific, measurable, realistic (within the child's capability) but not limited to current service provision.

The sections should not be limiting and in many ways it is less important which section a particular outcome is recorded in, for example, the need for accessible physical environment might be included under friendship, moving about by myself or self-care and life skills. It is not necessary to fill in each section unless it is relevant to the child/parent/s involved.

The summary section: This should detail those outcomes that the professional, child and his/her parents agree to work towards. This is completed in discussion with the child and his/her parent/s. There should not be a limit on how many outcomes should be recorded but it would be very useful to prioritise outcomes if there is a long list. If possible, major outcomes should be divided into sub-outcomes that are the steps necessary to achieving them. The summary section should also record who is to undertake specific actions. This may include the worker, a referral to another agency, the child and/or his/her parents. If at this stage it is not clear who exactly should be involved, the worker should put his/her name down to take the case further and identify the relevant agency the case should be referred to. The child and his/her parent/s rate how important different outcomes are to them at the moment. The priority should be recorded using a scale approach (H=high priority, M=medium priority and L=low priority). There should not be a limit as to how many outcomes are rated as high priority etc.

2. Desired outcomes for parents/carers: This section is used in exactly the same way as the previous section except that it aims to identify outcomes parents want to achieve in their caring role. Thus this section only ascertains parents' views.

3. Summary of assessor: This section at the end is where the professional judgements are recorded. Any differences of opinion between child, parent and professional could be recorded in here.

Using the Action Plan:

The format of this form mirrors the summary section of the core assessment form. It aims to provide a clear easy to follow summary of goals to be met, what actions have been agreed, the person/agency responsible and a target date. The care plan should be signed by the child (if appropriate) and his/her parent/s and be copied to them in a format of their choice.

Using the Review Plan:

The review document follows the same format as the earlier documents. It provides space to identify whether or not an outcome has been achieved and if not why not and what action is required and who will act. It also includes a section to detail any new or unmet outcomes. If the child and/or his/her parents' situations have changed dramatically, it may be necessary to complete additional core assessment and care plan documents. The review document should be copied to the service user but does not require their signature.

'WHAT CHILDREN AND FAMILIES WANT TO ACHIEVE'
Guidance notes for parents

Services in [your area] want to improve the way they work with disabled children and their families who use their services. This sheet gives you some information about a form they are going to be trying out and how to use it. The form is called: 'What children and families want to achieve?'

What does this tool do?

The form is designed to encourage a discussion between child, parent and worker around areas important to the child's life and between parent and worker on areas important to parents. The aim is to identify the key goals/outcomes the child and his/her parent/s want to achieve through service provision.

What do we mean by outcome/goal and sub-outcome/sub-goal?

Outcomes/goals can best be thought of as aspirations, the end products you want to achieve from a service rather than the provision of a service itself. For the child, this could range from wanting to make improvements in some areas of their lives, maintaining good and valued things, and in some cases, minimising deterioration in certain areas of the child's life. An example of an outcome for the child would be having opportunities to meet people and experience different activities. For parents, this could be anything in your life that has an impact on your and your child's life that you want to change or improve. You may think of 'smaller goals' and 'building blocks' that help your child and yourself in achieving 'bigger goals'. These are referred to as sub-goals/sub-outcomes. An example of this for a child would be 'finger eating' as a step towards 'eating independently'. You also have a chance to rate how important it is to achieve any outcome identified.

What will happen next?

If you and/or your child have identified areas in your lives that need intervention, your worker will record it (including differences of opinions). A process of negotiation will then follow which would result in a decision as to what will happen to support the achievement of those outcomes. This may or may not be finalised at the time of the assessment but your worker will involve you in that decision and notify you of the outcome of that negotiation.

It is important to know that identifying an outcome does not guarantee that the identified outcome would be achieved but it enables your worker to make a better judgement about how best the family can be supported.

What areas are covered?

The areas covered are drawn from research by talking to children, their parents and other informants (if children were unable to take part directly).

For children outcome areas include: health and well-being, safety and access, communication, social relationships and leisure, education and learning, and identity, social presentation and participation.

For parents they include: quality of life, physical health and emotional well-being, parenting, skills and knowledge in supporting the child's well-being, access to resources and how services make parents feel.

APPENDIX NINE

Dissemination

Dissemination

Published papers

Beresford, B., Tozer, R., Rabiee, P. and Sloper, P. (2004) Developing an approach to involving children with autistic spectrum disorders in a social care research project, *British Journal of Learning Disabilities,* 32*,* 180-185.

Rabiee, P., Sloper, P. and Beresford, B. (2005) Desired outcomes for children with complex health care needs, and children who do not use speech for communication, *Health and Social Care in the Community,* 13, 5, 487-487.

Rabiee, P., Sloper, P. and Beresford, B. (2005) Doing research with children and young people who do not use speech to communicate, *Children and Society*, 19, 385-396.

Accepted for publication

Beresford, B., Tozer, R., Rabiee, P. and Sloper, P. Desired outcomes for children and adolescents with autistic spectrum disorders, accepted for publication in *Children and Society*

Beresford, B., Rabiee, P. and Sloper, P. Families with a disabled child: developing a framework of parents' desired outcomes, accepted for publication in *Child and Family Social Work*

Submitted

Beresford, B., Rabiee, P. and Sloper, P. The lives and aspirations of children and young people with palliative care needs: children's and parents' accounts, submitted to *Palliative Medicine*.

Other

Sloper, P., Beresford, B. and Rabiee, P. *Desired Outcomes for Disabled Children and Young People.* Paper prepared for Special Educational Needs and Disability section of the Children, Young People and Families Directorate, Department for Education and Skills.

Sloper, P. and Beresford, B. *Defining ECM Outcomes for Disabled Children,* presentation to Maria Eagle MP, Under Secretary of State for Children and Families, 16 January, 2006.

Conference/workshop presentations

Beresford, B. *Disabled Children and Participation: Messages from research evidence and research methods,* Quality protects/SSI Regional Disabled Children's Event, September 2003: York.

Beresford, B. *Participation and Disabled Children: Lessons from research evidence and research methods,* Children's Participation Network Meeting (East Midlands Region), January 2003: Nottingham.

Beresford, B. *Consultation and Participation for Children with Special Needs,* Youth in the Community: Learning to Listen, April 2004, Inmarsat Conference Centre: London.

Beresford, B. *The Disparity of Service Delivery,* invited speaker at Conference: 'Seamless Services for Children with Disabilities', November 2004, IBIS Earls Court: London.

Beresford, B. *Supporting the Inclusion of Disabled Children in their Communities: What does research tell us?* Effective Inclusion: Best Practice Conference, June 2005: Nottingham.

Beresford, B. *Consulting with 'Hard to Reach Children': General principles.* Association of Children's Hospices Quality Assurance Training Day, January 2005: York.

Beresford, B and Rabiee, P. *Accessing the Views of Harder to Reach Disabled Children and Young People.* Social Research Association Annual Conference, December 2004: London.

Beresford, B. and Rabiee, P. *Involving Disabled Children in Research,* Mixed Methods in Health and Social Care Conference, July 2005: Cambridge.

Rabiee, P. *Accessing the Views of Children and Young People Who Do Not Use Speech for Communication,* Disability Studies: Putting Theory into Practice International Conference, July 2004: Lancaster.

Rabiee, P., *Consulting with Children Who Do Not Use Speech,* Association of Children's Hospices Quality Assurance Training Day, January 2005: York.

Rabiee, P., Beresford, B. and Sloper, P. *Desired Outcomes for Disabled Children: Indicators of well-being for disabled children and their families,* Childhoods 2005: Children and Youth in Emerging and Transforming Societies, 29 June- 3 July 2005: Olso.

Sloper, P. *Using Visual Methods to Facilitate Consultation,* Association of Children's Hospices Quality Assurance Training Day, January 2005: York.

Sloper, P. *Working With Very Young Children and Those With Profound Impairments,* Association of Children's Hospices Quality Assurance Training Day, January 2005: York.

Dissemination conference

Every Child Matters Outcomes: What do they mean for disabled children?

Held at the University of York, 5 May 2006. [This conference was fully booked, with a waiting list of over 100, so will be repeated later in the year].