Contents

Appendix 1- Letters of Introduction to potential participant families

1 From the Clinical contact within the PCT

Dear Parent,

I am writing to you from the Community Paediatric department of Norfolk Community Health Care to tell you about a RESEARCH PROJECT which will be taking place in this area. You will find a letter from Dr. Waterson and an information sheet about the study, enclosed with this letter.

Please will you read the information and then decide if you would like more information or would like to participate in this research. If so please **contact Dr. Peter Langdon on 01603 593599**

There is no need for you to agree to participate in this research and your decision as to whether to do this or not will not in any way affect the clinical care of your children. If you do decide you would like more information, Dr. Waterson will phone you and arrange a time to come and talk to you about it.

Norfolk Community Health Care has given Dr. Waterson permission to do this research and the study has been approved by the regional ethics committee. The findings from this study could help families with autistic children to cope better in the future .

Yours sincerely,

Dr. Melanie Bruce
Chartered Clinical Psychologist

2 letter from Dr. Waterson

Dear Parent,

I am writing to you about a research project which I am doing as part of a post-graduate degree at the University of East Anglia. I retired from NHS clinical practice after 35 years last year. Since then I have been studying for a post-graduate degree – a MD. This involves doing original research. I have had a special interest in autistic spectrum disorders, for many years as a Consultant Community Paediatrician, and am keen to do some research in this area. I will be the main researcher for this study but it is important to understand that I am in no way going back to clinical practice as a Doctor.

I am sending you an information sheet about the project, and also an information sheet for children. Please read the sheets and if you would like to take part or have more information please contact Dr. Peter Langdon on 01603 593599. He is a lecturer at the University of East Anglia and is also my research supervisor. He will ask me to contact you and I will arrange to come and discuss the project with you and if you want to take part I will ask you to sign a consent form.

I very much hope that you will be able to help me with this project.

Best wishes,

Yours sincerely,

Imogen Waterson

Appendix 2- Participant Information sheet for parents

Study Title: Coping strategies in families with more than one autistic child.

You are being asked to take part in a research study.

Before you decide if you want to take part, it is important for you to understand why the research is being done and how it will affect you.

Please take time to read the information sheet carefully.

You can talk to others about this research study if you want to; this can be anyone you like.

Please ask if there is anything you do not understand.

Thank you for reading this.

The Researchers

Dr. Imogen Waterson, Medical Doctorate student at the University of East Anglia, and recently retired as Consultant Community Paediatrician for Norfolk CHC

Dr. Peter Langdon, Lecturer in Clinical Psychology, University of East Anglia, the research supervisor for this study.
Phone contact for further information: 01603 593599
Address as above

What we want to find out:

We want to understand how families with more than one autistic child manage to cope with the difficulties they have. We also want to know about the strengths and strategies that you have which have helped you overcome some of the problems that might occur when you have an autistic child.

Why is this study important?

We know that the long term outcome for autistic children depends on how well they fit in with their families and how well the families cope with everyday problems. Very little is known about families who have more than one autistic child and how they manage to cope. If you can help us by taking part in this study we hope to be able to advise doctors and nurses about how to improve the care that is offered. The information will also be helpful to other families in a similar situation.

Why have you been selected?

Your family has been chosen because you are known to the Doctors and Nurses who work for Norfolk CHC. (This used to be called Norfolk Primary Care Trust) and have at least 2 children on the autistic spectrum.

Do I have to take part in this research?

No, of course not. Even if you agree to take part now, you can change your mind later. You do not have to give a reason if you do not want to take part. If you choose not to take part this will not affect your normal clinical care in any way. We will go through this information sheet with you and then ask you to sign a consent form if you wish to take part in the study.

It is important to understand that Dr. Waterson is doing this research as part of a University degree. She will not become an active clinical Paediatrician again. If any clinical problems occur during the research these will be referred on to the appropriate Doctor or Nurse.

What will happen?

Dr. Waterson will visit your house or you could choose to be seen in a clinic. Dr. Waterson will ask you some questions which might last for about an hour. These interviews will be tape recorded using an audio-tape recorder machine. The tapes will then be taken by Dr. Waterson to a secretary at the University of East Anglia where they will be typed.
Dr. Waterson will then analyse the information.

Once all the information is analysed you will be sent a rough copy of the information which is going to be published. If you do not like anything that is written you can ask for it to be left out or you can withdraw from the study.
If you choose to withdraw from the study, at any point, the tapes will be destroyed.

Who will be interviewed in my family?

We would like to interview at least one parent and both parents if they are both living at home. We are not interviewing Grandparents in this study unless they are the main carers of the autistic children.

We would also like to interview brothers and sisters of the autistic children if they would like to take part, and any children with an autistic spectrum diagnosis who are able to talk. Children should be over the age of two to take part.
I will also send you an information sheet for children which I would like you to show to your children. Children under 16 do not have to sign a consent form but I would really like them to feel they are actively agreeing to the study. This is called assent. If they are able to write their names they can do this on the children's assent form.

If children would like to take part but would sooner not speak, they could draw a picture of their family instead.

Payment

We will pay travel expenses to and from the clinic if you choose to be interviewed at the clinic. I am afraid there is no other payment for taking part in this study.

Are there any bad things that could happen?

No. You may find some of the questions a bit unusual but please answer them as well as you can.
If anything upsets you, we can stop, and you can talk to the researcher not on the tape.
If you want to talk to someone else about any issues that arise from the research you can be referred to a clinical psychologist who will see you on another occasion.

Are there any good things that might happen?

By agreeing to take part you will be helping other families who have autistic children.

Will my information be kept private?

Yes. All the information will be stored in a locked cupboard and any information that is stored on a computer will be protected by a password. Your name will not appear anywhere on the stored information. Each family will be given an identifying number and only Dr. Waterson and the secretary will know the code. If you change your mind and wish to withdraw from the research your information will be destroyed.
At the end of the research the type scripts will be held at the University of East Anglia in secure storage until they are destroyed.

If you do agree to take part in this study your General Practitioner will be informed. The reason for this is so that your GP knows that you are seeing someone about research and you might want to ask your GP about anything which bothers you about the study.

If any information about child safety comes out in the course of the interviews Dr. Waterson will have to notify the relevant authority.

If you want your child's school to know that they are taking part in a research study, this could be arranged. Mostly it will not be necessary to inform the school but if any child starts to have unusual behaviour it might be helpful if the school knew about a possible reason.

What happens at the end?

The results will be written up in a medical journal and you will have a copy.

Who is organising this research?

The University of East Anglia has agreed to this research and the research has been approved by the local Research Ethics Committee. No outside body is funding this research.
If this study is successful it may result in Dr. Waterson obtaining a postgraduate degree. The University of East Anglia carries out regular audits of research activities.

Contacts

If you want any further information you can contact Dr. Peter Langdon the research supervisor at UEA. His number is:- 01603 593599. If there are any questions that he feels would be better answered by Dr. Waterson, she will phone you back.

If you would like to take part in this study, please let Dr. Langdon know, on 01603 593599 so that Dr. Waterson can contact you and arrange a time when she can visit you at home and explain about the research in more detail. After she has explained more about the study she will ask if you are happy to sign a consent form before starting any interviews.

Complaints

If you have a concern about the study please contact Dr. Peter Langdon at UEA on 01603 593599 or email P.langdon@uea.ac.uk or email Dr. Waterson on I.waterson@uea.ac.uk

Appendix 3- Participant Information Sheet for Children

Please can you help me with a special piece of work called research?

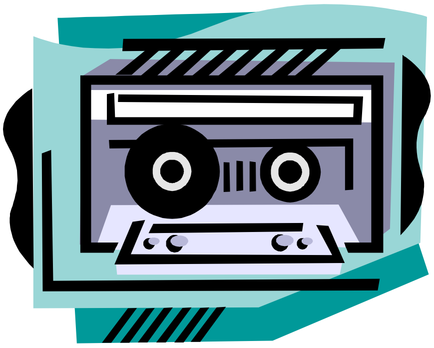
Who is doing this?

Dr. Imogen Waterson

As a Doctor I used to look after children with autism. Now I am trying to find out more about living with people with autism.

What will happen?

I will come to your house and ask some questions about what is good about having a brother or sister with autism and what is tricky.



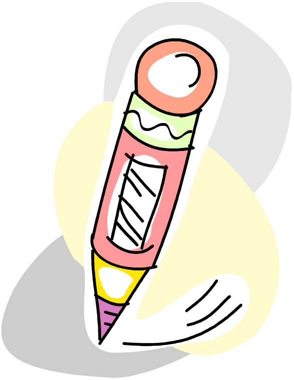
I will use a tape recorder while you are talking to me.

Why have I been chosen?

Because there are two or more people in your family with autism.

Do I have to do this?

No of course not. Nothing will happen if you say no. But you may prefer to do a drawing instead of talking to me.



If you say yes then I will ask you a few questions and you may be able to help other families like yours.

Will Mum or Dad or anyone else be told what I have said?

Only if you want them to know. Mum or Dad or anyone else in your family can be there while you talk to me if you want. Or you can choose to see me on your own.

What will happen after the talk is over?

The tape will be typed up and I will look at what you have said. I will work out what all your information means and then write about it. If you are worried about what I may write I will come and speak to you and read out what I hope to write before sending anything to Mum or Dad. Once you are happy I will send a copy of my writing to Mum or Dad and one for you.

What happens next?

I expect I will find out some helpful information and it will then be put into a medical magazine for other people to read. No one else will know that it is you that I am writing about and all the tapes will be kept private for a few years and then destroyed.

What do I do now?

If Mum and Dad are also happy to join in with this research they will phone me and I will arrange to come to your house to explain some more about what will happen.

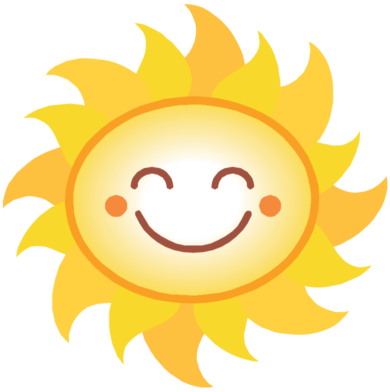
When I am at your house we will ask Mum or Dad to help you write your name on a special form that I will explain when I see you. Or just let me know that you are happy to speak to me when I see you.

Appendix 4- Participant Information sheet for Young Children

Hello. My name is Imogen.

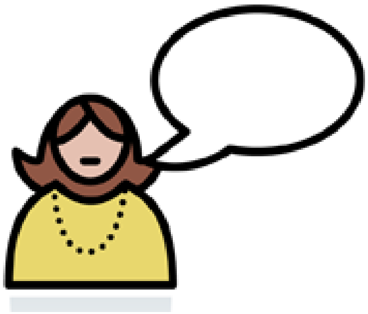
What is this for?

I will come and see you and Mum or Dad

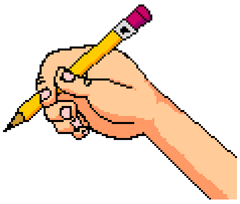


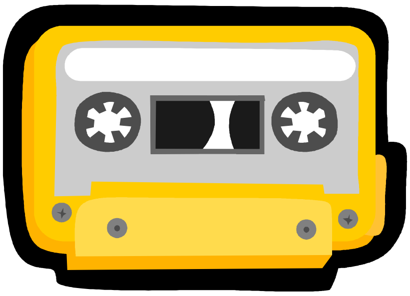
Would you be happy to join in?

If so I will come to your house.



We will talk and draw.





I will talk to Mum and record on a tape

Then I will go away

Appendix 5- Consent form for Parents

Study Title: <u>Coping strategies in families with more than one autistic child</u>

Name of researcher: Dr. Imogen Waterson

1 I confirm that I have read and understood the information sheet dated 14 09 2009 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3 I understand that the relevant sections of my children's notes and data collected during the study may be looked at by the researchers and individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my children's records if necessary ☐

4 I agree to my GP being informed of my participation in the study. ☐

5 I agree to my children taking part in this study. The following named children are included: ☐

----

6 I understand that if disclosures about child safety are made the researcher will have to notify the appropriate authority. ☐

7 I consent to the use of audio taping of the interviews. ☐

8 I agree to take part in the above study. ☐

------------------------------------	---------------------------------------
Name of parent	Date

Signature

------------------------------------	---------------------------------------
Name of person taking consent	Date

Signature

When completed, 1 for patient; 1 for researcher; 1(original) to be kept in medical notes

Appendix 6- Assent Form for Children

Project title: Coping strategies in families with more than one autistic child

Child (or if unable, parent on their behalf)/ young person to circle all they agree with:

Have you read (or had read to you the information sheet version 1: 25 06 09) about this project?
Yes/No

Has Dr.Imogen Waterson explained about this project ?
Yes/No
Do you understand what this project is about?
Yes/No

Have you asked all the questions you want?
Yes/No

Do you understand that it's OK to stop taking part at any time?
Yes/No

Have you had all your questions answered in a way you understand?
Yes/no

Are you happy to take part?
Yes/No

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Your name

Date

The doctor who explained this project to you needs to sign too:

Print name

Sign

Date

Thank you for your help

Appendix 7-Adult Interviews

Semi-structured Interview Questions for Qualitative study into families with more than 1 autistic child

1 Describe your family. How many children do you have and how many have a diagnosis of autism or an autistic spectrum disorder?

- How old was the first child when they were diagnosed?
- Who are the other children in the family?
- Are the grandparents very involved with the care of your children?
- Do you have other close relations who have an autistic child?
- Before your second child was diagnosed with autism did you have suspicions when that child was quite young that he or she might also have autism

2 Which was the first one to be diagnosed? Could you describe this process and how you reacted at the time?

3 Could you remember how long it took you to absorb the information about the diagnosis? What was the effect on your family?

- Did one of you come to accept the diagnosis before the other?
- Were there tensions between you as a couple at that time?
- How did the siblings react? - How old were they when you told them about the diagnosis?

4 When did you recognise that your other child/children might also have autism?

5 How did you react to this possibility?

- Was it harder or easier to accept the second child with the diagnosis?

6 Please could you describe to me how your family works from day to day?

7 Could you outline the most helpful things you have come across that make life easier for you?

8 If there were any changes that could be made to help you what might these be?

- Would you have benefitted from more support within the extended family?
- Would you have liked more support from the Health Service or Social Care?

9 Do you have any comments about the way professionals dealt with your family?

- Was there one particular service that you would have liked more of?
- Was there a service that you have heard about that does not exist locally that you would have liked?
- Are there any parts of the caring services that you found less useful and if so what were they?
- Can you make any suggestions about improvements to existing services?

10 Do you think your family has been strengthened by having autistic children and if so could you tell me in what ways this has happened?

11 Are there any special tips or hints that you would give to other families in the same situation as you?

12 How do you think your family copes with what several people see as a stressful situation?

13 Some families who are bringing up one or more disabled children speak about the extra closeness and warmth they have as a family. Could you describe any similar feelings you might have?

Appendix 8- Semi-structured Interviews for children

1 Hello. Please could you tell me about your family? Who lives at home?
2 Tell me a bit more about your brothers and sisters.
3 What is really good about living with -----------.+----------------?
4 Are there any problems about living with --------+--------------?
5 Do Mum or Dad sometimes get cross with-------+--------------?
6 What is it that makes them cross?
7 Do you ever wish you could change anything about how you live at home?
8 If you had a magic wand and you could use it to change something what would that be?
9 Do you have lots of friends at school?
10 Can you bring your friends home to play with you?
11 If there is something that really upsets you who would you talk to about it?
12 If you were talking to one of your friends about------------ what would you tell them?
13 Are you proud to have a brother/sister like-----------? Tell me what you are proud about.
14 I expect your brother/sister has to go to the hospital sometimes. Do you go too? Is there something about going to the hospital which you would like to change?
15 Does-------------sometimes go and stay with another family? What is it like when he is not at home? Do you think it is OK for him to have a special family that he visits?
16 What do you think will happen when all the children in your family leave home after they have left school?
17 What is the best thing about having a brother or sister like-------+----------?

Appendix 9- R+D approval letter

Dr. Imogen Waterson
School of Medicine,
Health Policy and Practice,
UEA
Norwich
NR4 7TJ

25 November 2009

Dear Dr. Waterson

Re: 2009GC09S (201-12-09) A Qualitative study into the coping strategies of families on realising that they have a second or subsequent Autistic Child.

STANDARD TERMS & CONDITIONS OF APPROVAL FOR RESEARCH

The Consortium's Research Governance Committee is responsible for the approval and monitoring of all research activities in the Partner Trusts.

The Research Governance Committee attaches the standard conditions set out in this letter to any approval. Approval of research within the Consortium is conditional upon acceptance of these terms and conditions.

1. Validity of approval
This approval is only valid if the research commences within one year of the approval date.

2. Safety and conduct of research
The Investigator will notify the Committee immediately if they are or become aware of any information which would cast doubts upon, or alter in any material way, any information contained in the original application, or a later amendment application, such as to raise questions about the safety and/or continued conduct of the research.

3. Observational or Non-Interventional Studies
If the research is classified as an observational or non-interventional study, this Approval is contingent on the following:

(a) the assignment of any patient involved in the research to a particular therapeutic strategy is not to be decided in advance by reference to the study protocol;
(b) the clinical care, management, investigation and supervision of any patient involved in the study must be determined by the clinical judgement of the treating clinicians and in accordance with the normal practice of the treating institution; it must not be influenced by or contingent upon the patient's involvement in the study.

4. Protocol and Protocol amendments

The Investigator must conduct the research in accordance with the Protocol. The Investigator will refer proposed amendments to the Protocol to the Committee and obtain the Committee's approval prior to agreement or implementation (except in cases of emergency where the welfare of the subject is paramount). This is in addition to the Investigator's responsibility to the MREC and /or Local Research Ethics Committee.

5. Serious Adverse Events

The Investigator will inform the Research Governance Committee of any serious adverse events relevant to any local participants in research within 24 hours of such events happening or of the investigator learning about them if later. This requirement is in addition to any duties the Investigator has to the Ethics Committee or the Sponsors of the research. The Investigator must also comply with relevant Trust incident reporting mechanisms.

6. Research funding

Any grant applications, or requests for funding, attached to this project will be submitted to the R&D office and are to be managed in accordance with financial probity (ie. compliance with Trust/ UEA policies and procedures).

7. Ethical approval

The Investigator will adhere to any applicable Research Ethics Committee terms and conditions of approval.

8. Monitoring

The Investigator will provide the Research Governance Committee with details of the progress of the research. This should be submitted on the Annual/Final Monitoring Report Form (available at http://www.nnuh.nhs.uk/docs%5Cdocuments%5C103.rtf), at intervals of one year unless otherwise specified by the Research Governance Committee.

If a research project is discontinued, the Research Governance Committee must be informed and an Annual/Final Monitoring Report Form submitted. This is in addition to any requirements from the Research Ethics Committee.

9. Research Audit

NHS organisations are required to audit a minimum of 10% of research projects in order to meet the Department of Health's research governance requirements. The Investigator agrees that the research project may be subject to audit, either as part of routine or 'for cause' audit activity. The Investigator agrees to cooperate with any audits or investigations undertaken by the host institution or regulatory authorities as required.

10. Roles and responsibilities

The Investigator will comply with the roles and responsibilities of the researcher, summarised in the attached document 'Roles and Responsibilities of the Researcher'. In particular they will ensure that all members of the study team are able by knowledge, experience, training and supervision to undertake the roles assigned to them.

11. Intellectual property rights

NHS responsibilities for intellectual property are defined in the NHS Executive's Policy Framework for the Management of Intellectual Property (HSC 1998/106).

Copies of this document, are available from the Research and Development office and the investigator is referred to the Intellectual Property Policy of their relevant Trust(s).

Intellectual property (patents, copyright, design rights, trade-marks, know-how) which arise in, or during, the course of an employee’s employment, belong to their employer, unless an existing contract overrules. By agreement to these terms and conditions the Investigator confirms his/her agreement to the allocation, treatment, management, handling and assignment of any intellectual property arising from the research in accordance with the intellectual property policies of the relevant host Trust.

In particular, where a research agreement relevant to the research requires that a relevant Trust should assign the rights to intellectual property arising from the research to the Sponsor of that research, the Investigator will cooperate to make that assignment effective in accordance with the terms of that agreement.

12. Publications

The investigator will inform the R&D office of any publications or publicity arising from the study and, at the request of the R&D office will use his/her best endeavours to ensure that the role of the host NHS organisation is acknowledged in any such publication or publicity.

13. Health and safety

It is the responsibility of the Investigator to be familiar with and comply with the Health and Safety Policies of the relevant Trust(s) copies of which may be accessed via the R&D office.

14. Research outside the NHS

The Investigator recognises that agreements and ‘approval’ granted by the Research Governance Committee apply to research activity on NHS premises involving patients and their tissues or records, clients, staff and NHS services. They do not apply to patients who are being treated privately nor does it extend, for example, to social services (except those working within Norfolk & Waveney Mental Health Partnership) or local education services. Separate agreements and approval for research access to these sectors will be required.

I confirm that I accept the above terms and conditions of approval.

Signed:…………………………………………………

Name:…………………………………………………

Date:…………………………………………………

Please copy this document returning the original to the Research Governance Committee office and retain the copy for your files.

Appendix 10-Letter of approval from Cambridge 4 Ethics Committee

Cambridgeshire 4 Research Ethics Committee

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597685
Facsimile: 01223 597645

02 November 2009

Dr. Imogen Waterson
Post-graduate MD student
School of Medicine, Health Policy and Practice
University of East Anglia
Norwich, NR4 7TJ

Dear Dr. Waterson

Study Title: **A Qualitative study into the coping strategies of families on realising that they have a second or subsequent Autistic Child.**
REC reference number: **09/H0305/73**
Protocol number: **1**

Thank you for your letter of 13 October 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC.

You suggested in the response to Committee letter that you could ask the families about their own support networks before the interviews and the Committee would like you to do this, confirmation is required.

On the PIS for children there is one typo: there is a letter 's' at the end of the last page.

The final version of the document should be provided to the committee for information.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*	
Compensation Arrangements	UEA	08 July 2009	
Compensation Arrangements	Tracey Moulton	08 July 2009	
Participant Information Sheet: for parents	3	14 September 2009	
Participant Information Sheet: for children	2	14 September 2009	
Participant Information Sheet: for young children	3	14 September 2009	
Participant Consent Form: for parents	3	21 September 2009	
Response to Request for Further Information	Imogen Waterson	13 October 2009	
Letter of invitation to participant	2	14 September 2009	
GP/Consultant Information Sheets	2	22 September	

		2009	
letter of invitation from NHS Norfolk	2	13 October 2009	
CRB Disclosure	Imogen Margaret Waterson	19 December 2008	
Covering Letter	Imogen Waterson	06 July 2009	
Investigator CV	Imogen Waterson	04 July 2009	
REC application	23056/48901/1/818	10 July 2009	
Summary/Synopsis	1	06 July 2009	
Participant Consent Form: for children	1	25 June 2009	
Semi structured interviews for children	1	25 June 2009	
Interview Schedules/Topic Guides	1	29 June 2009	
Peer Review	Michael Pfeil, Bruce Lindsay	23 April 2008	
Compensation Arrangements	MDU	27 March 2009	
Protocol	1	06 July 2009	
Educational Supervisor CV	Dr Peter Langdon	08 July 2009	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0305/73 **Please quote this number on all correspondence**

Yours sincerely

Dr Leslie Gelling
Chair

Email: Nicky.Storey@eoe.nhs.uk

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* "After ethical review – guidance for researchers"
Copy to:	Miss Tracy Moulton Research, Enterprise & Engagement Office The Registry University of East Anglia Norwich, NR4 7TJ Dr Peter Langdon School of Medicine, Health Policy and Practice University of East Anglia Norwich, NR4 7TJ

Cambridgeshire 4 Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 29 October 2009

Committee Members:

Name	*Profession*	*Present*	
Dr Leslie Gelling	Nurse/Senior Research Fellow	Yes	
Miss Carol Smee	Regulatory Advisor	Yes	

Appendix11:- Sample of Initial codes

Numbers of children
Head-banging leading to trance
Started rocking
Autism facts
neighbour gets help
Family composition
Timing post MMR
Age of diagnosis
Dad accuses Mum
Symptoms
Blamed bad batch of immunisations
Rocking
?deaf
compensation
Nothing wrong
mum reassures self
Facts about family
tragedy 2 eldest
Twins
story of the move
Confusion over congenital or acquired
Did not let kids mix
MMR
let them have a life
Regression
Neighbour persuasive
Unknown cause
social snobbery
Wakefield
bad behaviour of oldest
First symptoms
gives them a social life
Older sibs fine with MMR
parental disagreement
Guilt
Age at which IW met
M+F conflict
MGM dies
Secrets
house arrangements
M believed in immunisations
Mistake to abort
Good nurse

Believed I could change
Everyone against us
Child services could have been more helpful
plans for future
no illusions re future
OK initially
were the only ones
Early normality 1
twin initially slower
we will leave
Rocking
Sibs forced us off island
Mum mortified when told she did not love daughter
Nice here
Cot banging
loosening the reigns
Story of crash
Sky TV helpful
No grandparents
MGM suicide
Managed children ourselves
Views of family not for ss
Niece's children autistic
perception of ss family
Did not recognise symptoms
let down by ss
Did not want to recognise diagnosis
future plans
Compulsive disorder
sorted problems
A slice of Aspergers ourselves
Weird tendencies
more info needed
Parent's suspicions
support groups
Triple test
not about financial help
Positive feelings
we organised activities
need people to talk to
All turned red coat
Prove Drs wrong
children

Needs special school

Sample of Initial codes continued

mental capacity problem
People out there for him
needs to know life skills
We all cried
vulnerable
Talk to him like an ordinary child
future plans
Regression = autism
Mum determined
extended family size
Adaptations
no confidence in supply doctor
Changed everything
We were both matter of fact
religion no help to one
Had troubles
religion helps M
Older children looked after him
Elder ones brilliant
Positive reframing
Resilience
normalisation
Just dealt with no 3
Diagnosis different
Previous life experience was a preparation
Treat them as normal Philosophy tips
Dad praises Mum
Easier with more than 1
Sibs loved the twins
Church critical of family
Parents worried
Dilemma next stage
A special kid
Were not v structured
Needed one normal one
Give in to demands
next child is reason for existence
Relied on older ones
We’ve made it fine

Appendix 12:- Focused codes

Family facts: numbers of children, demography

Reactions to the diagnosis of Autism: age at diagnosis

Autistic symptoms: eg. deaf?,
rocking, regression, obsessions,

Severity of Autism and type

Beliefs about causes of autism

Positive emotions: relief, joy, determination, pride,
optimism, calm, mellow etc.

Negative emotions: guilt despair, disbelief denial etc.

Educational experiences- negative: bullying, teachers not understanding, placement refusal, teachers frightened

Educational experiences- positive: wonderful teachers, very supportive, helpful statements, good planning for transition

Practical activities: to improve wellbeing

Advice to new parents with an autistic child

Use of relatives and extended family: family support- grandparents far away, grandparents not understanding, helpful grandparents

Use of statutory services

Sources of helpful information

Changes to the environment

Sibling's feelings

Children's understanding of autism

Child protection issues

Immunisations

Life stories

Focussed codes continued

Death

Novel arrangements

Social services

Attitudes to professionals

Attitudes to family members

Additional diagnoses epilepsy, dyspraxia, constipation

Mental Health problems: In mother or in children

Information acquisition: the learning curve, the internet, the right amount at the right time.

Partners: splitting up, helpful, child minding

Colleagues: support,

Religion: positives, negatives

Normalisation

Appendix 13-Themed and Axial codes

1. The diagnosis and reactions to it- **Causal condition**

2. Number of children
3. Severity of Autism
4. Parents understanding of Autism
5. Children’s views of autism.
6. Autistic children’s views of autism
7. School factors

Context

8. Child protection
9. Mental health
10. Unexpected deaths
11. Partner leaving
12. Unexpected deaths
13. Added diagnoses

Intervening

Conditions

Themed and Axial codes continued

14. Family support	**Strategies**
15. Extended family	
16. Emotional coping	
17. Cognitive coping	
18. Practical coping	
19. Service support	
20. Buoyant coping:	**Consequences**
21. Quality of life	
22. Normalisation	
23. Positive reframing	
24. Family cohesion	
25. Perilous coping	Consequences
26. Family breakdown	

Appendix 14 Reflexive Notes

The following are selected brief extracts from the longer notes taken after each interview and show passages which helped to shape my analysis

Family 1.

‘Not a family that I have a clear memory of, probably because all the children were considered to be mild. This provoked thoughts about lack of support in general for ‘mild’ cases.’

‘FM1 gave insight in front of 1M that he feels she has Asperger tendencies.’

Family 2.

‘The current serene calmness is in contrast to my memory of earlier days and might just reflect the absence of children in the house or a genuine ability to rise above the former problems.’

Family 3 reflections.

I do not remember diagnosing 3 D as well fam. 2 or 4 and as both boys had high functioning ASD I had less to do with this family for follow up than some. They praised N. But most of all their own organisation and structure was their major coping strategy.
The family have agreed that I can visit them for follow up with Dad which is very kind. M3 said that her religious beliefs helped with own inner calm but were not a major factor in daily coping.
Delightful 2 boys; 1 verbally very able, but both with typically ASD socialisation problems. Chill out strategies with game boy and TV.

FU visit round trip 128 miles
Family all at home, very welcoming. House looked very organised considering they only moved in a few days ago. Garden still a building site.

Mr. 3 did not have many clear recollections around the time of diagnosis. He is a very organised man who expects the boys to behave. Most of the coping strategies had come from their own imposed structure and tight boundaries around the boy’s behaviour which the boys respected.

3T was in the room during the interview and sometimes interjected if he felt Dad had said something wrong.

I had only met Mr. 3 once in clinical practice at the feedback following diagnosis of T so interview was almost as though with a stranger.

Positive thoughts coming from family; but also major concerns about schooling, change and job for 3M.

Grandparents are an important resource but fairly distant. Family might have wanted some child minding but on the whole they don’t go out unless grandparents are staying.

Ability to go to MacDonald’s and holidays demonstrates organisation and social coping.

Family 4- extract

I thought she was coping much better than when I had last seen her as a patient when boy G was seriously undernourished ....She described progress in his affection towards her and various practical coping strategies for each day.

Is she really coping? She appears to be but in the past she was depressed and her nervous laugh sometimes betrays inner sadness.

Family 5- extract

- Parental recollections from 5+ years ago may have changed with time.
- Innovative ways of finding support eg. lodgers.
- Pragmatic approach to problem solving.
- Ability to go away without 5T is a major coping strategy.
- Massive support from school and LH to improve family functioning.

Family 6- extract

A major bonus was a conversation I had with Mum after the tape finished, in which she told me she would not have invited a researcher she did not know into her house. She also said she could not have talked freely about her emotions without having an existing relationship. She gave me a warm hug before I left and said she was please to see me again.

Family 7- extract

Another family where pragmatism reigns and religion is not a significant factor.

The house was tidy and well organised and Mum was clearly on top of her day to day routine. Although she was becoming increasingly frightened of P’s outbursts, and has to call on neighbours or colleagues if things get too much.

Family8- extract

Was it that I did not know this family before the interview? Had M given a franker account because she did not have to please me as a former patient? It would be helpful to have another family unknown to me to compare this with.

Family 9- extract

Another family which was previously unknown to me.
A coping family with wider family support in spite of split marriage. No one negative. A lovely atmosphere exists here. Pragmatism reigns.

Family 10- extract

Many stories I had not heard before.
Mum and GM interviewed together although M did most of the talking. They have a very close relationship.
Amazing calmness in spite of recent breakdown.
The human is very resilient as shown by this family, and capable of change.

Family 11-extract

A long outpouring of her story.
Showing considerable resilience in spite of 2 relationship breakdowns. 1 boy not at home and 3 autistic boys.
Living on the edge quite a lot but an air of serenity.
No major new insights. I think I have reached saturation, although the stories are all fascinating and one could continue for ever!

Other reflexive notes not family related

- Train journey to London: December 10.

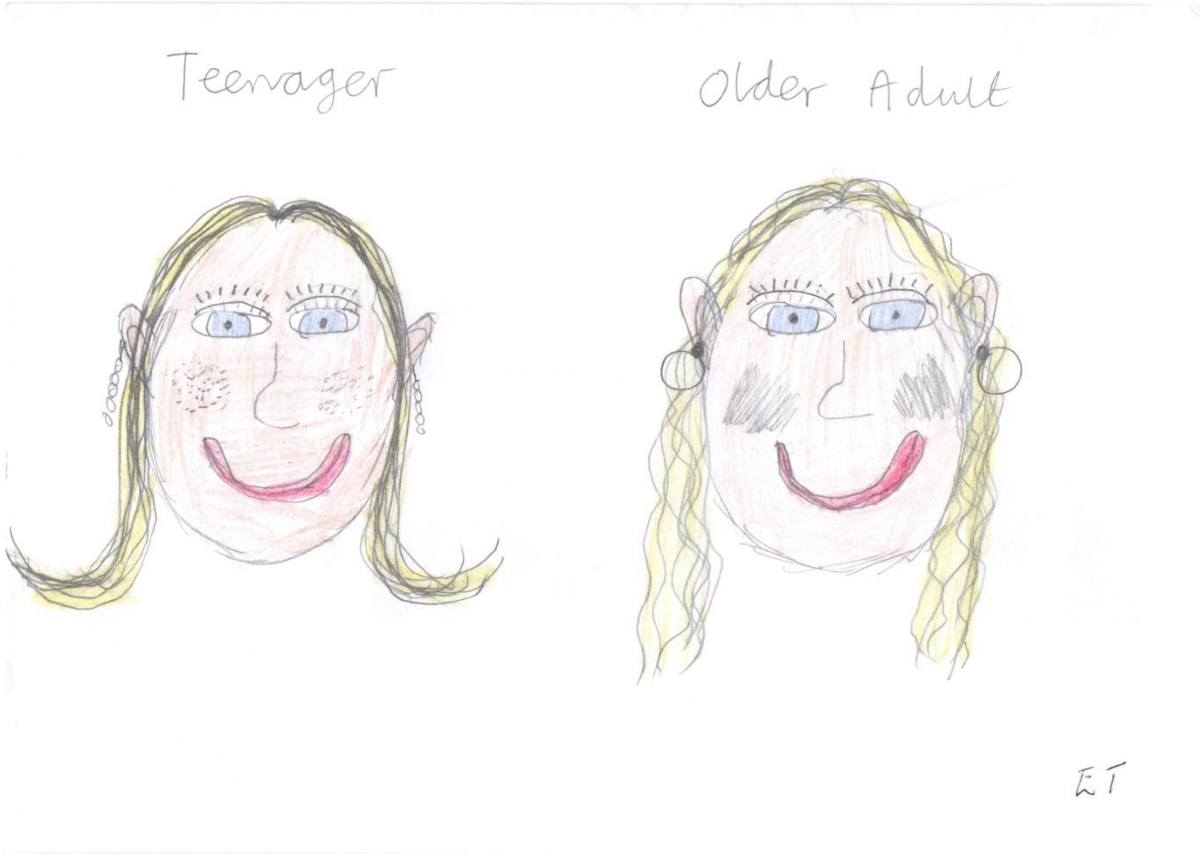
  A breakthrough today in my analysis, the idea of buoyant as opposed to perilous coping seems to encompass all the scenarios. An initial sketch of the two outcomes is promising.

- Feb 10: Worries over coding need to seek supervisor's support.

- March 11: Another eureka moment, by extracting all the relevant quotations and putting them together in one document the re-analysis is giving me much greater depth of understanding and some real messages are revealing themselves.

- May 11: Concerns that the results chapter is too long but I am very loathed to leave out all the juicy quotes.

Appendix 15 Children’s drawings



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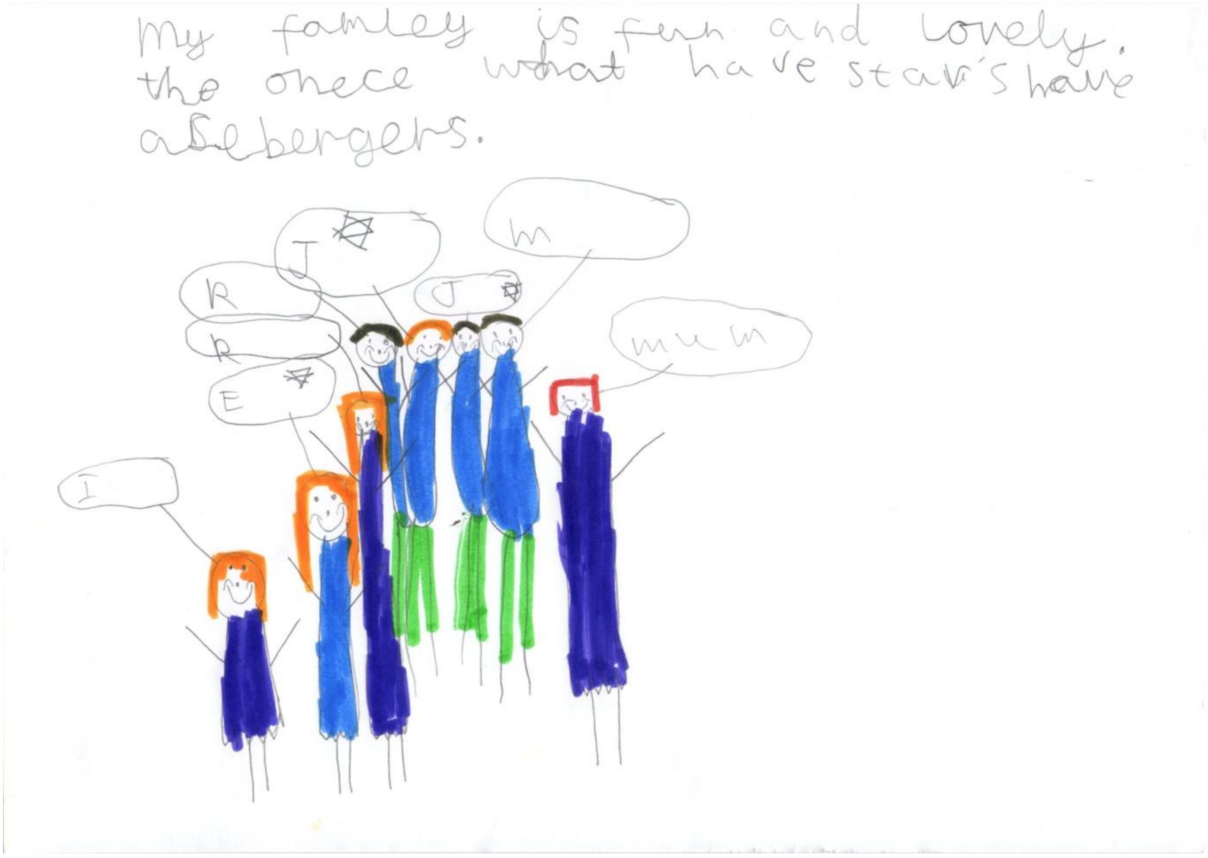
My famley is fun and lovely. the onece what have star's have asbergers.


J
JR
J
M
Mum
me
R
I
Dad


E