

**Bangor University**

## **DOCTOR OF PHILOSOPHY**

### **Sensory perceptual experiences in autism**

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## APPENDICES

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## **APPENDIX 1**

This appendix relates to Chapter 4, Study 2. It contains a copy of the Interview Protocol used to guide the interviews with participants with Autism.

**Interview Protocol**

**For interviewer only**

**Name:**

**DOB:**

**Age:**

**Sex:**                      **Male**                      **Female**

**Diagnosis:**

**By:**

**Date:**

**Subject Code/Identifier:**

**Date of Interview:**

**Other relevant Information:**

## Introduction

First of all I would like to thank you for agreeing to meet with me, and I would like to explain again why I asked if I could come to see you and talk with you.

I understand that you have talked with your (parents/ others) over the years about how you had difficulties during your childhood / still have some difficulties, because of Autism/ Asperger's Syndrome. I am interested in finding out from people like yourself more about these difficulties and how you see them. Only a relatively few people are as successful in overcoming their difficulties as you have been, and so I feel it is important to consult and learn from you. The aim is to achieve better understanding and support for people with difficulties like yours in the future.

In particular I wanted to talk with you about your sensory experiences - how you experience sounds, how you see things visually, your sense of taste and smell and of touch and so on. I want to ask you about these things because some people who have difficulties similar to yourself have described problems in these areas. For example, some people find certain kinds of sounds or smells or touch quite unpleasant or upsetting, particularly in childhood. On the other hand some others say that they are really fascinated by some types of sensation - certain sounds or smells or movements or by looking at certain things. I'm interested in finding out if any of these things are true for you.

**Q.1** Have you read about these sorts of experiences or talked with anyone else about them before?

(If yes, establish the details)

I have a considerable number of questions which I would like to ask you. It's not easy to say exactly how long it will take - somewhere between one and a half and two hours I should think at most. However I don't want you to feel hurried in any way.

I realise that some of the questions may be difficult to answer, that it is not always easy to put your experiences and memories into words in a way that makes sense. I want you to feel free to say things just as they come to you.

My main aim remember is to achieve a better understanding of your experiences and the way things have been for you and I do appreciate that these may not always easy to describe.

If you don't want to answer a question or if you are not sure about what to say, that's fine - just let me know and we can move on. Also if you want to pause at any time or ask me anything, or indeed stop altogether just say so. I would like to ask you first about your childhood and growing-up and then about what it is like now as an adult. Are you happy to do this with me now? Is there anything you want to ask me before we start?

### **General Questions re. Childhood**

I'd like to start now with the beginning of your life, with your childhood and work forward from there.

I expect your parents/ family may have spoken to you over the years about your childhood and what you were like as a child and the things you did? Is that right?

Well, what I would like to talk to you about are your own memories, as distinct from the things that your parents may have told you about but which you can't actually remember for yourself. Remembering things like this from the past can be difficult so you may want to think before you answer, so take your time.

**Q.2** Let's start with the very early years, the years before you started school.

**(a)** Can you tell where you were living before you started school? Your address at that time.

**(b)** Can you give me the names of three friends or neighbours at that time?

**(c)** Can you tell me about an incident, one incident, which you can remember from this period before you started school?

Prompts: Your first memory?

Involving a brother or sister ? (as appropriate)

[Why do you think this memory stands out for you?]

**Q. 3** Let's move on now to your primary school years between the age of five and eleven?

**(a)** Can you tell me the name of the first school you attended?

**(b)** Where was this school? (town or city)

**(c)** What age were you when you started at this school?

**(d)** Can you tell me the address you were living at when you started at this school?

**(e)** Can you remember the names of three teachers or friends from this school?

Prompts: The headteacher?

Your form teacher?

A friend?

**(f)** Can you tell me about an incident, any incident you can remember while you were at primary school?

[Why do you think this memory stands out?]

**Q. 4** Moving on now to your Secondary or Highschool years.

**(a)** What was the name of your secondary (or high) school?

[If attended a number of schools ask which school he attended at age 13 ]

**(b)** Where was this school? (town or city)

**(c)** How many examinations did you pass ? or What year did you leave school?

**(d)** What was the address where you were living while you attended Secondary school?

**(e)** Can you remember the names of three teachers or friends at this school?

Prompts: The headteacher?

Your form teacher?

A friend?

**(f)** I wondered if you can recall an incident from your time at secondary school and tell me about it. Any incident you can recall will do.

Prompts: Involving a teacher?

Involving a friend?

[Why do you think this memory stands out for you?]

**Q. 5** What were the things you particularly enjoyed or liked doing as a young child? Did these change as you got older?

**Q. 6** Were there things you disliked or found upsetting as a young child? Did this change for you as you got older?

### Sound

I'd like to ask you now about your hearing :

**Q. 7** Looking back, can you remember anything interesting or unusual about the way you experienced sound as a child?

Unusual compared to how sound is for you now?

Unusual compared to how it seemed for others?

(If yes, prompt re. details of experience and how it made him/her feel)

**Q. 8** Were there any sounds or noises that you disliked hearing?

**Q. 9** Were there any sounds or noises that made you feel uncomfortable or upset or frightened as a child?

**Q. 10** (i) Did peoples' voices bother you?

(ii) Dogs barking bother you?

(iii) The sound of the vacuum cleaner bother you?

(iv) Did loud noise bother you?

(v) Hair dryer?

(v) Any other noises or sounds?

**Q. 11** And now as an adult, is it the same for you now?

**Q. 12** As appropriate

a. Can you describe what it was/is about this/these sounds which you found/find unpleasant?

b. Did/Do you always experience this/these in this way?

Prompt: Did/Does it vary according to the situation?



- c. Can you remember exactly how it made/makes you feel when you heard/hear this/these?
- d. What did/do you do in this/these situation(s)?
- e. Did/Do you try to avoid these situations?
- f. How big a problem was/is..... for you?

Prompt: Did/Does it interfere with your life in any way?

Did/Does it make you anxious generally about situations where you might hear.....?

- h. Was/Is there anything you could/can do to stop (this/these) sounds affecting you in this way?

**Q. 13** Were there any sounds or noises which you very much liked to hear, that fascinated you as a child?

Prompt: Were there any noises or sounds you spent long periods listening to?

**Q. 14** Were there any particular sounds that were special or important to you in some other way as a child?

Are there any particular sounds that seem to immediately grab your attention or that you are easily distracted by?

Is this a nice feeling for you or do you find it a nuisance or annoying in any way?

**Q. 15** And now as an adult?

**Q. 16** As appropriate,

- a. Can you describe what it was/is about this/these sounds which made/make it/them so interesting/so special?
- b. Can you remember exactly how it made/makes you feel when you heard/hear .....?
- c. Did/Do you always experience these in this way or did/does it vary according to the situation?
- d. Did/Do you actively seek out these sounds, go out of your way so to speak, to hear this/these sounds?
- e. Did/Does it bother you if someone interfered or tried to stop you ?

**Q. 17**

a. Growing up were there any sounds which you could hear which others did not seem to notice?

(If yes, prompt: Can you describe this/them? Were there any others?)

b. Were there sounds which you seemed to hear before others could hear them?

**Q. 18**

a. Were there any sounds which others seemed to hear which you could not?

Can you describe this?

Were there any others?

b. Were there sounds which others seemed to hear before you heard them?

**Q. 19** Do you remember ever having difficulty hearing other peoples' speech?

In what sorts of situation can you remember this happening?

**Q. 20** Do you remember ever wanting to shut out or block out sound?

By putting cotton wool or something in your ears?

By putting your hands over your ears?

Was this something that happened a lot?

**Q. 21** Did you like any very loud sounds or noises?

Prompt: Did you play music very loud a lot?

What was it about the loudness that you liked?

**Q. 22** Did you like to listen to any very soft sounds?

Prompt: Did you like to play music very, very softly?

What was it about the softness that you liked?

**Q. 23** Were there any (other) sounds which you disliked because they seemed too loud?

**Q. 24** Did your hearing ever seem to play tricks on you at all ? For example

sometimes hearing things too loud and other times being scarcely able to hear at all?

**Q. 25** Did you have any problems hearing others speech in noisy, crowded places?

**Q. 26** Is it/are these things the same or different for you now as an adult? If different, in what way(s)? Why do you think this is so? Can you remember at what age this changed?

**Q. 27** As appropriate: How do you deal with these situations now as an adult?

**Q. 28** For use as appropriate if previous Q's do not elicit unusual descriptions of how sounds are perceived:

A. I am going to read you a short quote from a lady called Temple Grandin and I wondered if this rings true for you in any way or if you've had any similar type experiences ?

" My hearing is like having a hearing aid with the volume control stuck on ' super loud'. It is like an open microphone that picks up everything. I have two choices: turn the mike on and get deluged with sound, or shut it off..." (Grandin, 1992, p.16)

OR

B. (From Parent Report). Do you recall anything interesting or unusual about \_\_\_\_\_?

### **Vision**

I want to ask about visual things next:

**Q. 29** Looking back, can you remember anything unusual or interesting about the way you saw things as a child?  
(Prompt re. details and how this made him/her feel as appropriate)

**Q. 30** Were there any particular things you disliked or found unpleasant to look at?

Q. 31 Were there any things which you found frightening or painful to look at?

Q. 32 Did any colours bother you?

Did florescent lighting bother you?

Did car lights in the dark bother you?

Bright colours?

Q. 33 And now as an adult?

Q. 34 As Appropriate

a. How exactly did/does ..... make you feel?

b. Can you remember exactly what it was/is about..... that you found/find unpleasant/upsetting/ ..../?

c. Did/Do you always experience ..... in this way or was/is it only occasionally that it bothered/bothers you?

Prompt: Did/Does it vary according to the situation?

d. What did/do you do when this happened/ in this situation?

e. Did/Do you try to avoid situations where you might see ...?

f. Was/Is there anything you could do to prevent .... affecting you in this way?

g. Would you say..... was /is a minor or big problem for you?

Q. 35 Were there any things you particularly liked to look at, that you were drawn to or that fascinated you as a child?

Prompt: Were there things you spent long periods watching or looking at?

Do you find yourself easily distracted by any particular visual events or objects objects?

In what sorts of situations does this happen?

Does it feel comfortable when this happens or is it a nuisance?

**Q. 36** Did you like to watch things spinning?

Lights

Straight lines?

Patterns or colours?

Telegraph poles?

Shiny or colourful objects?

**Q. 37** And now as an adult?

**Q. 38** As appropriate

a. Can you describe what it was/is about this/these that made/makes them

so interesting?

b. Can you remember exactly how you felt/feel when you were/are involved in this activity?

c. Did/Do you go out of your way to .....

d. Did/Does it bother you if someone interfered/interferes or stopped/stops

you .....

**Q. 39** Do you remember your eyes ever 'playing tricks' on you as a child?

Prompt: Were there situations where suddenly you found yourself unable to see properly?

Can you describe this?

**Q. 40** a. Can you remember seeing things which others did not seem to be aware of?

Colours?

Detail?

b. Did others seem to see things which you didn't?

**Q. 41** Did you like being in the dark as a child?

**Q. 42** Were you frightened by the dark?

- Q. 43** Were there any television programmes or videos that you particularly liked to watch?  
What was it about these that you found interesting or enjoyable?
- Q. 44** Do you remember having difficulty judging how high or how wide things were?  
Did walking along kerbs or the edge of pavements bother you?  
Walking up or down stairs?
- Q. 45** Did you have difficulty judging size?  
Do you remember any occasions when you saw things as bigger or smaller than they really were?
- Q. 46** Were there any rooms or buildings that you didn't like to (i) look at or (ii) go into?
- Q. 47** Did you have difficulty following the lines of words on the page when you were reading?
- Q. 48** You have described how.....  
Is it/are these things the same or different for you now as an adult?  
If different, in what way(s)? Why do you think this is so?  
Can you remember at what age/when this changed?
- Q. 49** As appropriate  
How do you cope with these..... now as an adult?
- Q. 50** For use as appropriate if previous questioning does not elicit descriptions of unusual visual phenomena.  
A. I am going to read a short quote from someone called Darren White:  
" My eyesight blurred several times that day and once I could see no more than a yard in front....I broke my collarbone falling off a radiator. My eyes were showing a wide windowsill where the radiator was and I sat down falling off instantly."  
Have you ever experienced any problems with blurring or judging depth or anything similar to this? Had any accidents because of problems with your eyesight?

OR

B. (Based on Parent Report). Do you remember anything interesting or unusual about \_\_\_\_\_?

What was it about ... that ... ?

### Touch

I want to ask you next about your sense of touch:

**Q. 51** Looking back now, was there anything interesting or unusual about your experience of touch as a child?

(If yes, prompt re. details of experience and how it made P feel)

**Q. 52** Do you remember being bothered at all by touch ?

**Q. 53** What was it like to be hugged as a child?

**Q. 54** Did it bother you if other children touched you?

**Q. 55** Did it bother you if someone brushed up against you if you weren't expecting it?

**Q. 56** What was it like to have your hair washed/ your hair cut?  
What about having your face washed? Your toe-nails cut?

**Q. 57** Were there any materials or surfaces which you found unpleasant to touch?

**Q. 58** Were there any types of clothing that you didn't like to wear?

**Q. 59** Did changing your clothes or wearing brand new clothes bother you?

**Q. 60** Did you enjoy going barefoot in the sand or grass or did it bother you?

**Q. 61** Did it bother you if your hands were dirty or sticky?

**Q. 62** Were there any foods that you disliked ?

Why was this?

**Q. 63** Did wearing shoes or socks bother you as a child?

**Q. 64** Did you like to be tickled as a child?

**Q. 65** And now as an adult are any of these things true for you now?

**Q. 66** As appropriate

a. How exactly did/ does ..... make you feel?

b. Can you remember exactly what it was/is about..... that you found/ find

unpleasant/ upsetting/ ..../?

c. Did/Do you always experience ..... in this way or was/is it only sometimes that it bothered/ bothers you?

Prompt: Did/Does it vary according to the situation you are in?

d. What did/ do you do when this happened/ in this situation?

e. Did/Do you try to avoid situations where you might ...?

f. Was/Is there anything you could/ can do to prevent .... affecting you in this way?

g. Would you say this.....was/is a relatively minor or quite a significant problem for you (at that time)?

**Q. 67** Was there any sort of touch which you really craved as a child?

**Q. 68** Was there anything which you particularly enjoyed the feel of or any sort of touch you remember really enjoying as a child?

Were there any textures that seemed to particularly grab your attention/ that you were easily distracted by?

In what sorts of situation did this happen?

Was it a nice feeling?/ Did you find it a nuisance?

**Q. 69** Did you like to roll up in a blanket or cover yourself with sofa cushions or anything like that?



Q. 70 And now?

Q. 71 As appropriate

- a. Can you describe what it was/is about ..... which you liked/like so much?
- b. Can you remember exactly how it made/makes you feel when you .....
- c. Did/Do you go out of your way to .....
- d. Did/Does it bother you if someone interfered/interferes or stopped/stops you doing this?

Q. 72 Would you say you were sensitive to pain as a child?

Q. 73 Do you recall situations where you hurt or injured yourself in some way?

Do you remember what you did when this happened?

Did you cry or scream?

Did you tell anyone?

Q. 74 Is it/are these things the same or different for you now as an adult?

Why do you think this is so?

Can you remember at what age/when this changed?

Q. 75 As appropriate

How do you cope with these..... now as an adult?

Q. 76 For use as appropriate if previous questioning does not elicit unusual description of sense of touch:

A. I am going to read a quote from a lady called Temple Grandin and I wondered if you have ever experienced anything similar to what she describes:

" I pulled away when people tried to hug me, because being touched sent an overwhelming tidal wave of sensation through my body. Small itches and scratches that most people ignored were torture. A scratchy petticoat was like sand paper rubbing my skin raw. Hairwashing was also awful. When my mother scrubbed my hair my scalp hurt." (Grandin, 1989).

OR

B. ( Based on parent report)

Do you recall anything unusual about \_\_\_\_\_ from your childhood?

What was it about ... that ... ?

### Taste

I'd like to focus on your sense of taste now:

Q. 77 Looking back was there anything interesting or unusual about the way things tasted to you as a child?

Q. 78 What sorts of things did you like to eat?

Q. 79 Were there any tastes which you were particularly fond of as a child?

Q. 80 Would you say there was a taste which you actually craved as a child?

Q. 81 Has this changed for you now as an adult?

Q. 82 As appropriate

a. Can you remember what it was about ..... which you liked so much?

b. Can you remember how it made you feel when you .....

c. Did you go out of your way to .....

d. Did it bother you if someone interfered or stopped you doing this?

Q. 83 Were there any tastes which you really disliked ?

Q. 84

a. How exactly did ..... make you feel?

b. Can you remember exactly what it was about..... that you found unpleasant/ ..../?

Q. 85 Is it/are these things the same or different for you now as an adult?

If different, in what way(s)? Why do you think this is so?

Can you remember at what age/when this changed?

**Q. 86** As appropriate  
How do you deal with ..... now as an adult?

**Q. 87** For use if previous questioning does not elicit unusual descriptions of taste.

A. Donna Williams describes her sense of taste deserting her;  
" On automatic pilot, a fork was lifted by my hand to my mouth and ate something. I had no idea what it was." (1994, p.87)  
Have you ever had this sort of experience?

OR

B. ( Based on parent report)

### Smell

I'd like now to ask you about your sense of smell.

**Q. 88** Do you remember anything unusual or interesting about the way things smelled to you as a child?

**Q. 89** Would you say you were sensitive to smell?

**Q. 90** Were there any smells that bothered you ?

**Q. 91** Were there any (other) smells which seemed overpowering or unpleasant e.g. perfumes or household smells?

**Q. 92** And now?

**Q. 93** As appropriate

- a. How exactly did/ does ..... make you feel?
- b. Can you describe exactly what it was/is about..... that you found/find unpleasant/upsetting ?
- c. Did/Do you always experience ..... in this way or was/is it only sometimes that it bothered/bothers you?  
Prompt: Did/Does it vary according to the situation?

- d. What did/do you do when this happened/ in this situation?
- e. Did/Do you try to avoid situations where you might feel ...?
- f. Was/Is there anything you could/can do to prevent .... affecting you in this way?
- g. How big a problem was this for you?  
Did/Does ..... interfere with your life in any way?

**Q. 94** Was there anything that you particularly liked the smell of as a child?

**Q. 95** Were there any smells which were important or special to you in any other way?

**Q. 96** And now as an adult?

**Q. 97** As appropriate

- a. Can you remember what it was/is about ..... which you liked/like so much?
- b. Can you describe how it made/makes you feel when you .....
- c. Did/Do you go out of your way to .....
- d. Did/Does it bother you if someone interfered/interferes or stopped/stops you doing this?

**Q. 98** As a child were you aware of smells and odours which others did not seem to notice?

**Q. 99** Did others notice smells that you were not aware of?

**Q. 100** You have described how.....

Is it the same or different for you now as an adult?

If different, in what way(s)? Why do you think this is so?

Can you remember at what age/when this changed?

**Q. 101** As appropriate

How do you cope with these..... now as an adult?

**Q. 102** For use if previous questioning does not elicit any unusual descriptions.

- A. I'm going to quote from someone called Georgina Stehli. I wondered if you have experienced anything similar to this?  
" ...smells like deodorant and aftershave lotion, they smell so strong to me I can't stand it, and perfume drives me nuts." (Stehli, 1991, p.187)

OR

- B. ( Based on parent report)

### Proprioception

I'd like to ask you now about body movement and how this felt to you as a child.

- Q. 103** Looking back can you remember anything unusual or interesting about how your body felt to you as a child?

Prompt: Your arms and legs for example?

- Q. 104** Were there any movements or activities which you found unpleasant or which you remember being bothered by as a child?

**Q. 105**

- a. Did lifts bother you?
- b. Did heights bother you?

- Q. 106** And now as an adult?

**Q. 107** As appropriate

- a. How exactly did/does ..... make you feel?
- b. Can you describe what it was/is about..... that you found/find unpleasant/upsetting?
- c. Did/Do you always experience ..... in this way or was/is it only occasionally that it bothered/bothers you?

Prompt: Did/Does it vary according to the situation?

- d. What did/do you do when this happened/ in this situation?
- e. Do you try to avoid situations where you might feel ...?
- f. Was/Is there anything you could/can do to prevent .... affecting you in this way

g. Would you say this was only a relatively minor problem for you or a big problem for you at time?

**Q. 108** Were there any movements or activities which you particularly liked to do as a child?

**Q. 109**

a. Did you like to go on fairground rides?

Which ones did you like best?

b. Did you like to spin yourself round?

c. Did you enjoy being on a swing?

What did it feel like?

**Q. 110** When you were upset or distressed was there anything you could do to help you calm down?

**Q. 111** Were there movements you did when you were agitated or excited?

Did you do this at other times?

Why do you think you did this?

What did it feel like?

**Q. 112** Is it/are these things the same or different for you now as an adult?

If different, in what way(s)? Why do you think this is so?

Can you remember at what age/when this changed?

As appropriate

**Q. 113** How do you cope with ..... now as an adult?

**Q. 114** For use as appropriate if previous questioning does not elicit descriptions of sense of body/ movement.

A. I'm going to read a quote from someone called Donna Williams :

' Grinding my teeth kept disturbing, unpredictable, and meaningless outside noise from coming in. Singing a repetitive tune and humming continuously did the same. The tapping gave a continuous rhythm and stopped the unpatterned movement of others from invading.' ( Williams, 1994, pp.29-30 )

Have you had any experiences similar to this?

OR

B. ( Based on Parent Report)

Some children/adults like to \_\_\_\_\_ . Was/Is this something you liked to do?

General

**Q. 115** Do you remember any situations where things would just blank out on you?

For example where you might be listening to something and it would suddenly blank out and then come back again or maybe where you are looking at something and suddenly you don't see it and then you can see it again?

**Q. 116** Have you had any experiences of senses getting mixed up - Where sound might produce sensations of colour?

**Q. 117** Would you say you were easily distracted by sights and sounds and smells as a child?

**Q. 118** Some children have particular fears in childhood, like being scared of feathers or elevators for example. Do you remember having particular fears as a child?

**Q. 119** Quite a few people have repetitive behaviours that they do when they are nervous or upset, things like biting their nails or pacing up and down. In my case for example I .....

Do you have any habits like this?

Why do you think you do this?

How does it make you feel when you do this?

Are you aware at the time that you are doing this?

Other people have habits or routines which help them relax, is there anything you like to do like this?

**Q. 120** Did you like to collect things as a child?

Can you remember why you liked to collect \_\_\_\_\_ in particular?

Was there a toy or some other object you can remember being very attached to?

What was it about \_\_\_\_\_ that particularly appealed to you?

**Q. 121 As appropriate**

- a. Looking back over the things you've described about (seeing, hearing etc.) which would you say was the biggest problem for you?
- b. Now as an adult, would you say this is still a problem for you in your day to day life?

We have talked a lot about sensory experiences but obviously these are just one aspect of your life - family, school, work, interests, friendships and so on are among other areas. Looking back on your life up to this point, and if you had to choose just one area, what would you say was the thing that has caused you the most difficulties?

And what would you say is the thing which has been most positive for you?

**Conclusion**

We have talked a lot now about you, and you have answered a lot of questions, is there anything else you would like to tell me which you feel is important for me to know about how these things are for you?

Is there anything you would like to ask me?

Thank you very much for talking with me, for sharing your experiences. If you are happy with the arrangement, I will send you a written report on the outcome of this research when it is completed, and invite your comments on it. In the meanwhile you have my number if you would like to contact me for any reason, to talk about our interview today or any queries or concerns you might have arising from it. In particular if you find there is anything that bothers you from our discussions or anything you are not quite happy about, please do let me know.



## **APPENDIX 2**

This appendix, relating to Chapter 4, contains a copy of the University of Wales Ethics Approval Letter for Studies 2 & 3.



Ysgol Seicoleg  
Prifysgol Cymru Bangor  
Bangor, Gwynedd LL57 2DG

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Ffôn Rhyngwladol: +44 1248 382211  
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e-mail: [pss029@bangor.ac.uk](mailto:pss029@bangor.ac.uk)  
<http://www.psych.bangor.ac.uk/>

March 6, 1996

Ms. Meena O'Neill  
School of Psychology  
University of Wales  
Bangor  
Gwynedd  
LL57 4UQ

Dear Colleague,

Your research proposal (referred to on the attached sheet) has been reviewed by the School of Psychology Ethics Committee and they are satisfied that the research proposed accords with the relevant ethical guidelines.

If you wish to make any substantial modifications to the research project please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if participants experience any unanticipated harm as a result of taking part in your research.

Good luck with your research.

Kath Chitty  
Coordinator - School of Psychology Ethics Committee

### **APPENDIX 3**

This appendix relates to Chapter 4, Study 2. It contains a copy of the letter inviting participants to participate in the research study.

School of Psychology  
University of Wales, Bangor  
Bangor  
Gwynedd LL57 2DG

Dear (Name),

I'm writing to you to invite you to take part in a research study which I am carrying out.

I would like to talk to a number of people with Autism or Asperger's Syndrome about their experiences of sound, vision, taste, smell and sense of body movement/ awareness. I want to do this because some people with Autism / Asperger's Syndrome who have written about their lives have described difficulties and unusual experiences in these areas. For example, some people describe finding certain sounds or particular types of touch unpleasant. Others say that they are particularly drawn to, or fascinated by, certain sensations, for example smells or light patterns or the feel of certain objects. However as yet we do not really understand what these experiences are like, or how common they are among people with Autism/ Asperger's Syndrome. Some people say these type of experiences are a nuisance, others that they are a pleasure and I would like to know about this too.

What you have to say about your own experiences in these areas may add greatly to our understanding of this subject, and also to our understanding of what it is like to have Autism/ Asperger's Syndrome. As a result I hope that it would mean better understanding and support for people with Autism/ Asperger's Syndrome in the future.

If you agree to take part in this research it will involve three things:

- You being interviewed about your sensory experiences - what you remember from childhood and your experiences now as an adult.

- Your parents being interviewed about their memories and observations of your sensory reactions
- Asking Professor (Name) for information from your case notes about these areas.

The interviews and the review of your notes would be carried out by myself and all information treated in the strictest confidence. Participation in this research is voluntary. You should feel free to accept or decline this invitation.

I attach an Information Sheet for you to read which gives further details of the study. If after reading this letter and Information Sheet you are happy to participate in the study (and I very much hope that you will be), please sign the consent form which is attached and return it to me in the stamped addressed envelope provided.

I've also written to your parents giving details of the study and asking them in the event that you say yes to the study, if they would be willing to take part in the parental interviews. Once I receive your consent form, I will contact you and your parents (if they are willing to take part) by telephone to arrange a date and venue for the interview. I shall be happy to travel to meet you at your home or other venue that suits you.

If you have any queries or if you would like to talk to me about the study, please feel free to give me a ring at xxx(daytime) or xxx(evenings).

Thank you for the time you have taken to consider this request. I hope I shall have the pleasure of meeting with you as a participant in this research.

Yours sincerely,

Meena O'Neill  
Chartered Clinical Psychologist and Research Fellow

## **APPENDIX 4**

This appendix relates to Chapter 4, Study 2. It contains a copy of the Information Sheet sent to participants explaining the nature and purpose of the research. It sets out what would be involved for participants taking part in the study.

## **Information Sheet**

**Title of Research:** An Investigation of Sensory-Perceptual Experience in Autism.

**Name of Investigator:** Meena O'Neill

**Position :** Chartered Clinical Psychologist & Research Fellow  
Gwynedd Health Authority / University of North  
Wales at Bangor.

### **Background to and Purpose of Research**

A number of published autobiographical and other first-hand accounts by people with Autism/ Asperger's Syndrome contain descriptions of unusual sensory-perceptual experiences (e.g. Williams, 1994; Grandin, 1992). These unusual sensory-perceptual experiences include hearing, vision, touch, taste and smell. Examples might include hyper-sensitivity to certain sounds, experiences of sensory overload, or being particularly fascinated/ drawn to sensations such as light patterns or the feel of certain textures. However as yet we do not really understand what these experiences are like or how common they are among people with Autism/ Asperger's Syndrome. The purpose of this research then is to explore the existence of these experiences among a group of people with high-functioning Autism/ Asperger's Syndrome with a view towards achieving a better understanding of them .

### **Description of study**

The study would involve me interviewing you about your childhood and current sensory experiences. In addition, with your consent your parents would be interviewed separately about your sensory reactions as a child, and Professor (Name) asked your early clinical case notes analysed for relevant background and developmental information from your case notes where this is available.

In order to ensure full and accurate representation of your responses and views all interviews will be tape recorded for later transcription.

Ethical approval has been obtained for this research from the National Autistic Society and it is being carried out with the full support of Professor (Name) from whose caseload participants will be invited to take part.

### **Participation in the Study**

In order to take part in the study you must be over the age of 16 years and have received a diagnosis of Autism or Asperger's Syndrome. Written consent will be required from both you and your parents prior to your inclusion in the study. Participation in the study is voluntary and you should feel free to decline to take part, or to withdraw from the study at any time.

### **Interview process/sequence**

Once you have indicated your willingness to take part in the study and have given your consent in writing I will:

- write to your parents setting out the purpose and nature of the research and invite them to take in the study.
- If your parents indicate their willingness to participate I will contact them to make arrangements for meeting with them to hold the interview. I will be happy to meet with your parents at their home or other venue of their choosing. It is anticipated that this interview will take somewhere between one and a half and two hours to complete.
- I will then contact you again to make arrangements for meeting with you for the interview. Again I will be happy to meet with you at your home or other appropriate venue. It is anticipated that the interview will take somewhere between one and a half and two hours to complete though this may vary slightly from one interviewee to the next.



## **Confidentiality**

Your identity and that of your parents will be protected at each stage in the research process. Any quotes taken from interviews and used in writing up the research will be presented anonymously.

All information will be treated confidentially. All tape recordings and transcripts will be labeled with date and a subject code only and all reasonable efforts made to ensure their safe storage e.g. stored in a locked cabinet in the University office.

## **Feedback of Results/Outcomes of study**

You will receive a written report setting out the main research findings. In addition it is my intention to publish and disseminate the findings of this research as widely as possible not only among the academic community but among people with autism themselves and their families.

## **Background of Investigator**

I am a Chartered Clinical Psychologist and member of the British Psychological Society, bound by the Society's Codes of Professional and Research Conduct. I trained with Professor (Name) in 1980-1981 and since that time through my clinical work I have met a considerable number of children and adults with autism and their families. In addition I was for a number of years involved in the development of services for people with autism in the west of Ireland where I worked.

Currently I work part-time as a Clinical Psychologist in the area of Learning Disabilities and part time as a researcher in autism. The research described here is being carried out as part of my Ph.D. studies at the University of Wales in Bangor.

## **Queries**

If you have any questions or queries which you would like to discuss before deciding about whether or not you would like to participate in the study, please feel free to contact me at the following number:

xxx ; Mon. - Fri. ; (9.00 am -5.00 p.m. )

If I am not available when you call please leave a message and contact number and I shall get back to you as soon as possible.

**If you decide you would like to participate in this research please complete and return the attached Response Slip in the pre-paid envelope provided.**

On receipt of the response slip I will contact you to discuss further arrangements for your participation in the study.

Thank you very much for the time you have taken to consider this request. I do hope I shall have the pleasure of meeting you as a participant in this research study.

**Signed:**

**Meena O'Neill**

## **APPENDIX 5**

This appendix relates to Chapter 4, Study 2. It contains a copy of the Response Slip that participants returned in order to confirm their interest in taking part in the research.

Response Slip

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

I would like to take part in your research study " An investigation of Sensory-Perceptual Experience in Autism".

My contact phone number is \_\_\_\_\_ .

Please indicate times which would best suit you for the investigator to contact you at this number in relation to this study:

Mondays                      Time:

Tuesdays                    Time:

Wednesdays                Time:

Thursdays                  Time:

Fridays                      Time:

Saturdays                    Time:

Sundays                      Time:

Signed:

Date:

## **APPENDIX 6**

This appendix relates to Chapter 5, Study 3. It contains a copy of the letter inviting parents to participate in the research study.

School of Psychology  
University of Wales, Bangor  
Bangor  
Gwynedd LL57 2DG

Dear Mr. & Mrs. (Name),

Thank you for indicating your willingness to consider taking part in my research study. I enclose an Information sheet which sets out further details of the study.

As we discussed on the telephone I'm interested in exploring the area of unusual sensory-perceptual experiences in Autism/Asperger's because a number of people with Autism/Asperger's have written about this area. Some of these experiences are described as problematic e.g. finding certain sounds painful ; others are described as enjoyable e.g. being drawn to or fascinated by certain light patterns or textures . However it may be that not all people with Autism/Asperger's have these experiences and I'm interested in exploring this too.

In addition to asking people with Autism/Asperger's Syndrome themselves about these things I felt it would also be useful to ask parents as well, since they are likely to have a wealth of knowledge about their son or daughter which might contribute to our understanding in this area. I was also concerned that some parents might well be aware of questions or topics connected to sensory-perceptual phenomena which I should avoid discussing with their son or daughter for fear of triggering an obsession or possible upset and for this reason also, I felt it wise to talk with them.

My main aim in carrying out this research is to achieve a better understanding of the experience of having Autism/Asperger's Syndrome and I hope that this will then in the future feed in directly to how we support children and adults with this disability and their families.

Participation in the study would involve me interviewing you and then (Name), with each interview taking approximately between one and a half

and two hours. I would be happy to travel to your home to do the interviews or another venue if this suited you better.

If after reading this letter and information sheet you would be happy to participate in the study, please sign and return the Consent form which is attached and return it to me in the stamped addressed envelope provided. In addition I enclose a letter and information sheet for (Name) and a consent form for him to sign and return if he is happy to take part. I would then contact you again by telephone to arrange an interview date.

If you have any queries or if you would like to talk to me about the study, please feel free to give me a ring at xxx(daytime) or xxx(evenings).

Many thanks for considering this request.

Yours sincerely,

Meena O'Neill  
Clinical Psychologist and Research Fellow

## **APPENDIX 7**

This appendix relates to Chapter 4, Study 2. It contains a copy of the Consent Form to be signed by participants agreeing to participate in the research.



PARTICIPATION IN RESEARCH: AN INVESTIGATION OF SENSORY-  
PERCEPTUAL EXPERIENCE IN AUTISM

CONSENT FORM

I, the undersigned have read the information provided setting out the purpose and nature of this research study. I understand that participation in the study involves three main strands:

Interview with my Parent(s)

Interview with Myself

Review of my Clinical Notes held by Professor (Name)

I understand that I may withdraw from the study at any stage in the research process.

I ..... agree to participate in this study,

Signed:

Date:

## **APPENDIX 8**

This appendix relates to Chapter 4, Study 2. It contains a copy of a Reflexive Log written after an interview summarising the main issues arising from the interview.

**Post-Interview Log: Summary Form**

Participant: C

Date of Interview : 10.3. 1998

*Main issues from interviewing process:*

Participant C seemed positive and willing in his approach to the interview. He was interested in the research and asked about details such as how many interviews had been conducted and so on. I had the feeling that his answers were honest and that he worked hard during the interview. However C was extremely slow in formulating and in articulating answers to questions in a way that made the interview quite laborious. His speech was slow and pedantic and very quiet. His eye contact was poor when listening and he showed a number of motor mannerisms such as finger-flicking. C's mother said that this presentation was quite usual for him. Conversation dominated by question and answer. I missed an opportunity to ask C about tip-toe walking and odd posture of holding hands at chest level. Exchange flowed best when C talking about his current course at college.

C showed poor ability to reflect on his experiences and was unable to provide detailed descriptions of his sensory experiences. At times C described instances from his childhood that he had been told about and was open about the fact that he himself did not remember them. On a number of occasions I wondered if his reply of 'don't remember' masked real difficulties in finding words to express himself.

*Main themes*

C showed poor ability to recall specific incidents from his childhood on the autobiographical memory interview questions. C described aversive experiences of some very specific sounds in childhood but was unable to say what it was about these sounds that he found difficult or details of how they impacted on him. He says he disliked touching money and buttons as a child but again was unable to say why these were unpleasant to him. He described a series of food fads such as wanting to have ketchup / gravy / custard with meals everyday for long periods. Definite feel that these problems were

confined to childhood and that he has grown out of them. He sees himself as having a poor sense of smell. Fear of going down escalators he described as the biggest problem because 'there might be no other way'. He described liking the sound of buses and going on buses, enjoys watching night scenes of streetlights in the dark and looking at telegraph poles and straight lines such as railway lines. Likes bus timetables and bus routes. He says he doesn't often feel pain but did talk about feeling pain when he trapped his fingers in a car door as a child. Stereotypic movements when agitated help him to calm down. Slowness in getting changed a problem for P.E.

*General*

C very disabled in social interaction. Struck again by the variability in this 'able' group in terms of verbal skills and ability to reflect on experiences. Confirmation from his report of a number of sensory difficulties and behaviours but little phenomenological detail.

## **Appendix 9**

This appendix relates to Chapter 4, Study 2. It contains a summary of the main categories within each modality, and a number of cross-modality categories, which emerged from the analysis of the data in Study 2. These categories are documented with illustrative verbatim data from which they derived. These categories were subject to further analysis to arrive at the analytic account presented in Section 2, Results, Chapter 4.

## **Sound**

### **Distorted sound**

This category relates to descriptions by participants of an experience of sound as distorted, blurred or confusing. In the absence of 'active listening' or effortful concentration on an event or activity a number of participants describe their experience of the sound environment as blurred, distorted, confused and without meaning.

B: Yea,.... it's, I suppose it's as if you're hearing something through the loudspeakers and the echo has been turned up, so that if you're in a bit of a daydream - you know if you're drifting off to sleep or you're in a bit of a daydream and what you hear around you might not be the way you're really used to hearing it if you're more, in a more alert state, it's kind of a bit blurred. Yea, I think things did tend to blur together slightly, especially when I wasn't concentrating. (Right). Anything I was concentrating on I could kind of, I could work at but anything I wasn't concentrating on basically used to blur together (OK) 'cos I hadn't yet developed my automatic perceptual processes.

Participant B identifies this difficulty with making sense of sound as part of a wider problem in the automatic processing all kinds of incoming information from the environment and parallels the experience with that of the blurring of perception which occurs through peripheral vision:

B: Well, you know if you're looking at one thing, you're looking at an object and then there's also what's around your field of vision, your field of vision has a peripheral part to it, how much can you tell me about that ? How much can you tell me about what you can see out of the corner of your eye (not very much probably). I suppose it was the same for me when it was to do with things I didn't happen to be concentrating on at the time, whether it be sounds or what people

were doing or anything (right). If you can put that into an auditory form you might kind of see what I mean.

These accounts suggest that this phenomenon occurs in situations in which Participant B is not actively listening or concentrating. Participant D also describes blurring of sound within a similar context:

D: Sometimes (blurring), especially if I'm not like thinking about sounds, not trying to listen to anything...

A number of factors were described as contributing to variation between and within participants in the occurrence and degree of this experience.

Participant G (who also describes the phenomenon as part of a wider problem with distortion of sensory information in several modalities or sensory overload) identifies an association with an emotional state of anxiety and worry:

G:... When I'm worried, people can be talking to me, and to me their voice is going up and down, when it isn't, just 'cos I'm worried. When I start to get worried I feel all sorts of sensations - one of them is that sounds suddenly seem too loud or too soft and it's just a feeling of confusion....I sort of feel like somebody would be claustrophobic with everything closing in, things seem to go too fast for my eyes and sounds go too fast for me to hear them properly and it all becomes a big blur as it were, and it's a sort of scary feeling.... It happens with visual things as well, yea.

Participant F (who has had fluctuating conductive hearing loss in childhood) describes a disconcerting experience of confused sound in specific public places such as restaurants. He reports a need to actively focus in on just one sound source in this situation:

F: Yea, the sound's still, the whole sounds still going on behind it but I still have to focus on the one sound, I can't hear the whole thing, I have to focus in on someone's private conversation which is not on!

\*R: And would that distract you from following a conversation say at your own table?

F: Not really, I think it sort of helps me really because there's not the confusion of the sounds round me, I know where it's coming from.

Participant B indicates that overall background noise levels affects the degree of distortion experienced:

B:...yes, some places were quieter than others, some places were a bit noisier

This experience of sound as distorted is described by participants as unpleasant to varying degrees from Participant G's description above of 'a sort of scary feeling' to Participant B's description of it as a source of distraction or nuisance:

B: Sometimes it would be unpleasant in the way that I found it , well I suppose irritating like it was distracting me, a constant distraction. Other times, pleasant or unpleasant?...I'm not sure I would call it either pleasant or unpleasant really, just a bit of a nuisance sometimes.

### **Distractibility**

This category relates to participants descriptions of difficulties in achieving or maintaining concentration to specific events or tasks because of distraction or interference by the wider auditory environment. This category contrasts sharply with participants description of a state of intense absorption in an activity in which they are very difficult to distract.

This phenomenon of distractibility (which might be conceptualised as impaired automatic selective attending) is described by participants in a number of ways. Participant D describes the experience of being 'open' to all sensory perceptions when not actively engaged in an activity.



D: Yea, I'd become easily distracted, like see everything, like try to pay attention to everything at once sort of...

Participant B described a difficulty in screening out background sounds in order to focus or concentrate on one aspect of the sound environment sound:

B: I mean that could have been the source of, that could have perhaps been part of the reason why I couldn't concentrate on certain things, or why my concentration might have been poor in many areas. If there's, I mean if you're in a social situation and there are people talking all over the room, you try to focus on just the sound of the voice you're meant to be listening to and cut out all the rest. For me I've had to, it's taken practice, it hasn't come automatically (Right) - maybe it has, but not to the same extent.

This difficulty in screening out background sounds subsumes aspects of experience which might be regarded as common sensory -perceptual experience. Participant B for example describes how this difficulty in screening out background sound is accentuated with increased volume of background noise but also in the case of background voices a small number of background voices may be more distracting than many:

B: It could be at times, yea, it could be, depending on volume as well. If the cumulative volume of the voices around me was louder or if there were few voices in fact - if there were many, many voices, then they kind of merge into one another and it's not so bad, but if there's just two behind you, or just one or two that's distracting you, that can be more distracting than if there are many.

Nevertheless there is a strong sense in which screening out background sounds in order to selectively attend to one thing is described by participants as particularly problematic for them:

G:...I can be put off what I'm doing...sort of a conversation or trying to do a piece of work, if there's something going on outside or somewhere else, it can be quite off-putting even when it isn't to other people.

A number of factors were described as contributing to increased difficulty in maintaining concentration or attention to task. Participant G identified unexpected or unfamiliar sounds as especially distracting because they provoked unease or anxiety:

G: Well, yes, I'm quite easily distracted by sounds 'cos I want to find out sort of the source of it when I hear it. It worries me if I can't place it. I think it's just the unexpected again, a sound that I immediately recognise is OK but if I hear something that I'm not quite sure what it is, then I won't be comfortable enough to get back. I'll stop and listen to it and have to think or maybe ask someone else "what's that" and often be quite unable to do anything until I have sorted out exactly what it is.

\*R: So that leads to anxiety...

G: It does, it's not knowing what it is really.

\*R: Would that, if you were trying to work or if you were in a conversation, actually interfere?

G: Yes, definitely.

Participant F describes a similar susceptibility to distraction by sounds which trigger an intellectual curiosity or need to identify the source of the sound. This susceptibility is described within a context of hyperacuity for these sounds:

F: I think I have to sort of, sort of have to know where the noise is coming from and how the noise is being made and that sort of, like if I hear the fax go for instance down there, some noises I can pick out when other people can't which is quite strange. I'll sort of go to a hearing test and say oh I can hear noises that other people can't hear but on the hearing test it's very strange that my hearing's below

normal....I don't think there are any noises in the house and I don't know what they are.

For Participant G anxiety contributes to increased difficulty in screening out background sounds leading to a need to deliberately shut out all sound from outside, a sense of 'all or nothing hearing':

G:...but I think when I'm especially anxious, it can be like that and I feel that I either have to listen to everything and it's just like the sense of having my acute hearing I have normally I can hear everything outside as well as inside - or shut it off - I can't focus on the one thing that I want to be doing it's sort of everything or nothing.

The degree of cognitive demand of a task or activity is also identified by Participant G as contributing to heightened awareness of and distractibility by background sound and a need therefore to shut it out:

G: If I'm concentrating on some.... yes, sometimes because I'm able to do several things at once I can quite happily be listening to the radio or watching the television while I'm doing sort of a schoolwork activity that doesn't involve thinking, copying something out of a book or doing something that requires very little sort of brain power but when I want to concentrate because I want to learn something or because I want to read a book more seriously that if I was just reading it with the radio on, I then become very aware of background sound.... and want to get rid of it all

Sustaining attention over time was described as problematic and for one participant sustaining attention to voice/other's speech especially difficult:

D: I think it's just when I'm doing the same thing for a long time, I tend to focus on other things (Right).

G:...I find it very hard to concentrate on a voice like other people would find it boring to listen to someone who was only speaking in a

monotone, I find it particularly hard to concentrate at all for any length of time.

The source of distraction may not necessarily be an external event.

Participant G describes his own thoughts as distracting in trying to follow a conversation:

G:...but I think the main problem with speech, I mean I can hear lots of voices in my head telling me what to do all the time and it's very hard to have a conversation with someone when there is someone else seemingly talking in my ear, perhaps just building up my judgment of this person, sort of saying this person's a liar or something, it's very hard to hold a conversation when I'm hearing voices all the time like that I think (right, OK) - which come more when I'm nervous....I think it's my thoughts - voices is the wrong word, I mean I'm using that because I once read something about schizophrenics (oh right) were like that and it gave the example how difficult it is to have a conversation when there's someone else talking into your ear but I think it's perhaps more thoughts but it's sort of things inside my head make it difficult for me to concentrate on what the person's saying

Participants descriptions suggest a sense of being at the mercy of this susceptibility to distraction. Participant D describes a phlegmatic acceptance of the phenomenon while Participant G describes consequences in terms of anticipatory anxiety which in turn feeds into a spiral of distractibility in certain situations:

D: Well it's just that my attention shifts to something else, sort of, on it's own...it's just something that happens.

G: Yes, I mean, I suppose and if I'm worried that it's likely to happen, then it's more likely to happen - if I'm having a conversation when I think I've got to pay attention to what's going on, I've got to appear to be you know responsive, I'm always worried that something might happen that will make me, not lose interest, but switch interest to

somewhere else. (OK, OK) And perhaps the more worried about it I am, the more likely something is to affect it.

**Failure to hear or register sound**

This category encompasses participants descriptions of the experience of hypo-reactivity to sound: failure to, or delay in hearing sound around them. In sharp contrast to descriptions of distractibility, participants describe the experience of being so engrossed in thoughts or activities that they fail to or are delayed in hearing or 'registering' sound. This includes quite dramatic examples of failure to respond to sound:

B: Actually one of my teachers at special school told me once that she was standing almost right behind me in the corridor and saying "Hello, B., hello" and I was giving no response whatsoever and it was as if I hadn't heard her and I said "I don't remember that".

Participants locate this phenomenon quite clearly in an attentional framework rather than at the level of the mechanics of hearing, making a distinction between hearing sound and registering sound:

B: I don't think I could ever physically switch it off but it's just, it's about limited capacity of attention. Sometimes I used to be so interested in whatever I was doing on my own at the time that I'd recruit almost, about 95% of my attention resources to it (right) and what I had left wouldn't be enough to, even for someone to break in to what I was doing, unless they actually shook me or something!

D: (Pause) Well if I start thinking about like something I can quite often just like stop hearing anything around me (right, right). I can still hear it, I just don't like register anything.

Participant G's account of this phenomenon suggests that awareness of the auditory environment may be particularly affected. Lack of awareness of sound may occur even when information from vision is present:

G:...somehow or other you're not aware of any sounds at all and think that I've gone completely deaf but it is obviously that someone in front of me is talking because their mouth's going up and down or it's obvious that there's something that's making a noise in the room because I can see it (right) but I can't hear it at all. But that's usually because I've been wrapped up in my own thoughts inside myself and it's hard to sort of focus down on what's going on everywhere else I think.

The effect of this intense absorption varies from the dramatic 'not hearing' described by B above to a delay in processing or becoming aware of 'outside' sound:

D: Well, when that happens, I'm focused on something, I usually focus on it for about a second longer before I realise it (right, right) it's like I sort of wake up again really.

This analogy of 'waking up' is mirrored by other participants who also describe the effect of intense absorption in terms of an altered state or experience akin to daydreaming:

B: I must have been in a real daydream at the time. (Right) I must have been completely withdrawn into... in my own world.

In this state distractibility is very much reduced. Participant B suggests that a delay in processing or waking up to sound may lie behind a lack of startle response to very sudden loud sound:

B: Umm,..... I don't know, I don't think I ummm, I don't think I tend to get a shock when I hear something that loud.... It's almost as if I require a certain amount of processing time and by the time I've processed it, actually my mind is so busy working out what it is that's made the noise, that it doesn't occur to me to jump.

These descriptions suggest that intense absorption and failure/delay in hearing sound arises involuntarily as a result of active engagement in an activity and is especially pronounced in childhood:

D: Well basically [distractible] if I was not doing anything 'cos as soon as I'd do something I'd become very difficult to distract when I was young.

However, in certain circumstances participants also describe a deliberate 'switching off' or blocking out of background sound in order to achieve this state of perceptual awareness with regard to sound.. This is described as a mechanism to minimise distraction from the auditory environment, to enhance selective attending to one event or activity or to cope with other aversive sounds or unwanted intrusions. This is achieved through a variety of strategies including deliberately focusing on one sound or activity, physically blocking out sound (e.g. fingers in ears) or cognitive strategies to 'switch off' background sound.

Participant F indicates that deliberately focusing on just one sound can be helpful in dealing with a confusing auditory environment:

F: In restaurants I always have to listen one thing, I can't sort of hear it as a whole, as a whole big thing.

Participant B recalls how repetitive humming of a particular piece of music helped him 'cut out' unwanted intrusions and demands:

B: It used to come out overtly, I used to hum it [Beethoven's Violin Concerto] on the way to school but, yea, it was, I might just be humming it, but inside my head I could hear the whole melody. I could hear the whole piece and I suppose that used to, that used to feel quite good because it was cutting out all the things that I didn't want to know about.



Participant G describes his use of a combination of physical and mental strategies to help himself focus on his 'internal' thoughts:

G: Mmm, I think if I jaw-drop slightly, I don't know I think there's something in your head that opens up or shuts down, that it's almost as if that puts a slight buzzing in my ears I think.... Umm, something I sort of think mentally but then sort of move my mouth slightly. I mean I'm not quite sure what it does but it's like that, it means that I can hear my internal thought clearer and it shuts out outer thoughts slightly more.... It's just that slightly concentrating I think about it and hear a sort of slight click in my ears and that helps me to concentrate, focus I think.... Yes, it's almost like switching off (Ummm). I do it if I'm trying to think something in my head and I can't hear properly, I can't hear myself think, because other people are talking, then I'll do that and that helps me hear my own internal thoughts clearer.

### **Effortful 'Interpretative Attending'**

This category refers to participant descriptions of needing to effortfully concentrate or deliberately focus on sound in order to make sense of it. Participants accounts such as those outlined above explicitly and repeatedly refer to the need for active listening or deliberate and effortful concentration in order interpret, make meaning from, and efficiently respond to the auditory environment. This can be conceptualised as a necessary action or strategy to deal with the subjective experience of phenomena such as those outlined above and an underlying impairment in the 'automatic' ability to selectively and flexibly attend to auditory information. It subsumes managing strategies previously described in relation to these phenomena. However, a number of participants particularly highlight difficulties in following others' speech and the role of others in facilitating this process of interpretative attending.



Participant B and Participant D both highlight the need for others to be within focus physically and to get their attention directly before they can follow what is being said to them:

B: I would think if there's someone talking behind me it would make it quite a lot more difficult because it would mean that they haven't first engaged my attention (right). I have, to really hear something, to analyse it and make sense of it, really I had to be focused on it.

D: Sometimes when people don't like facing me when they're talking to me, I have difficulty.

Participant B clearly sets this process of selective or 'interpretative' attending within a developmental framework and as a skill which becomes more efficient and practiced with age;

B: Anything I was concentrating on I could kind of, I could work at but anything I wasn't concentrating on basically used to blur together (OK) 'cos I hadn't yet developed my automatic perceptual processes.

### **Negative case example**

Participant G, elsewhere in the interview describes an ability to follow a number of conversations at once that would seem to suggest that at other times there is an unusual *facility* in attending to a number of different sources at once. He identifies hyperacuity and possibly salience/motivation as factors contributing to this. However, further exploration of this ability was not addressed in the interview and consequently this phenomenon and how it relates to the category of 'Effortful Interpretative Attending' is not understood.

G: I really mean for that by conversation a greater distance than I'd expect to hear it (right, aha) or when someone's being sort of deliberately quiet, especially sort of at school if people are whispering

and there's lots of people talking, I can usually hear all the conversations going on between all the people

\*R: Right, all at the same time!?

G: All at the same time, yes.

\*R:... So you're able to follow a number of conversations at once, is that ?

G: Yea, that's what I mean.

### **Hyper-acuity**

This category refers to participant descriptions of 'hyperacuity' in hearing, either as a general characteristic or in relation to specific sounds or qualities of sound.

Participant G describes his hearing, especially when younger, as hyperacute in that he heard sounds at a lower volume, at greater distance and a greater range of sound frequency than others:

G: Yes, I certainly can hear approaching things earlier than other people, whether it's someone calling from a long way away or a car on the road, I can hear it before other people can.

G: I mean I've got, I used to have a very acute sense of hearing umm you know wherever I was in the house I could usually hear what was going on and that's slightly decreased and (right) I mean I can hear sounds from a higher frequency than a lot of people and that's perhaps why sounds that are very shrill and piercing ring in my ears a lot more because I can obviously hear them as they go slightly higher and other people can't hear them when it goes beyond their range, people have a sort of certain range.

Participant G suggests that his exceptional hearing contributed to an unpleasant experience of loud sound:

G: Umm, I don't like very loud sounds, I mean when I was younger I didn't used to like even hearing music if it was turned up too loud

because I had quite a good sense of hearing (right) it would give me sort of a slight earache to hear a loud sound (OK)

Participant B also describes an unpleasant experience of loud sounds and implicitly assumes a degree of 'hypersensitivity' in his perception of loudness compared to others:

B: Umm, oh yes, yes,... as a family we went to a concert,... and throughout most of the concert I had my fingers in my ears because the music was so loud,...and not long after that I remember being in an ice rink disco type of place with this family support group and a lot of the time I had my fingers in my ears then and people used to think it was a bit odd and they thought perhaps I was saying I didn't like the music but it wasn't that at all, it was the fact that it was too loud...

Participant D and Participant F both describe hyperacuity for particular sounds:

D: I used to hear sort of ringing noises especially out of computer monitors that other people couldn't hear. (Right) Which was rather strange... when I was younger, at primary school I remember being able to tell if a computer was on from quite a long way away by the sound, I don't think it was one of these advanced ones with a ventilation fan or anything, it just seemed to hum to me, other people couldn't hear it. I don't know if that's normal or not.

F:...But if we're in the house, Mum can't hear, Imogen can't hear and Dad can't hear and the fax is going, I sort of run down here and there's a huge long fax and if a digital watch is going on, like I've got one in there which was my watch, and I just leave it around now, it always goes at one minute past five and whenever that goes off I always have to, I always know what that is. (Uhum) I don't think there are any noises in the house and I don't know what they are.

In the case of both these participants the sounds described may have a particular relevance or salience to them. Participant D has a long-standing interest in computers. Participant F elsewhere describes himself as interested in electronic or mechanical things and there is a strong sense in which curiosity about the nature of these sounds and a need to identify or place them may have contributed to their salience for him. As earlier described, Participant F indicates that this hyperacuity contributes to distractibility and exists in the context of a degree of hearing loss for low frequency sounds.

A heightened salience or relevance of sound is also identified by Participant G as a factor in his ability to have heard conversations about himself through walls and at considerable distance. He describes this process as happening almost subliminally with no awareness until later 'prompted' to become aware:

G: Yes, that's what I mean by it being acute (right) and I usually think it seems to be, I don't listen out for it, but if someone's talking about me or else about something that's sort of relevant to me I'm more likely to have picked it up (right) rather than if they weren't.

G: No, I mean I don't listen out for them but I seem to have heard them if they have said something that's about me 'cos I'll usually comment on it later (right, OK) but I haven't necessarily heard it all the time.

Participant G continues to see himself as having exceptional hearing but suggests that aspects of this ability have attenuated to some degree as he's got older:

G: only in the sense that now I can't hear things that are far away as much as I used to be able to. (Right) I mean not to any great extent, I mean I can still hear quite well...

Participant D's hyperacuity for computer sounds was observed as a primary school child. Participant F's account suggests that his exceptional hearing of

house related sounds is a continuing phenomenon. Participant B's descriptions of difficulties with loud sound are described in the past tense.

**Problematic hyper-sensitivity (sound)**

This category relates to participants' descriptions of unpleasant hyper-reactivity or sensitivity to particular sounds or qualities of sound.

These sounds are described as 'unpleasant' and as sounds to which participants have a heightened responsivity and which can produce high levels of anxiety or distress which would seem to go beyond the 'teeth on edge' experience with which many people might identify e.g. chalk on blackboard experience. Identifying the underlying basis of the aversive response to certain sounds was not necessarily straightforward. Participant C for example was unable to articulate what it was about the sound of the lawnmower, drills and other electrical equipment which was extremely distressing to him in childhood. Participant B. offered a number of explanations for his dislike of women's voices, one of which appeared to have been influenced by his recent reading of a pop psychology book on gender differences. Nevertheless a number of specific attributes of many of these problematic sounds, either on their own or in combination can be identified from participants accounts.

*Loud sounds*

A number of participants describe a difficulty in tolerating loud sounds. Participants B and G both report a strong general dislike of loud or high volume sound such as loud music or noisy environments. As previously described their accounts suggest that because they experience sound louder than others because of general hyper-acute hearing, loudness which others can tolerate or enjoy is perceived by them as 'too loud'.

In addition Participants F in describing an aversive experience of vehicle noises highlight loudness as a problematic quality:

F: Oh yea, I think loud car noises when I was in a petrol station, that sort of thing, was sort of quite upsetting...and motor bike engines revving up and things... Just certain engines, cause bigger cars like

lorries and things I didn't like (uhum) as they go past they make that horrible noise.

*Unpredictable or unexpected sound*

Participant G indicates that his difficulty with sudden loud sounds is due as much to their unexpectedness as to their volume:

G:.... I think most of all it comes as a shock, umm because I'm not expecting it. The sounds I don't like are always unexpected (right) and so I'm sort of, especially a good example is at school if someone's talking normally and then someone has to raise their voice to shout at someone, I'm not expecting that (right) and it comes almost as a shock to my senses and that could be why I find it quite uncomfortable (right) - perhaps I hadn't you know read the signals that led to it leading up to that (right) or perhaps other people would do or perhaps other people wouldn't be bothered at all but I've never liked loud sounds at all.

Here Participant G links the perceived unpredictability of sound with the core social impairment in autism: a difficulty in reading and understanding social-emotional dynamics and other aspects of social communication.

*High-pitched/ Reverberating sound*

Participant G suggests a heightened sensitivity to the reverberative quality of some high-pitched sounds, sounds which might commonly be experienced as unpleasant:

G: I mean I can hear sounds from a higher frequency than a lot of people and that's perhaps why sounds that are very shrill and piercing ring in my ears a lot more because I can obviously hear them as they go slightly higher.

G:... more so if they were things that went on and on and on, errr, that were sort of reverberating, something like a fire alarm that sort of keeps going...

*Sounds associated with negative or unwanted experiences*

In recalling a strong dislike of the sound of women's voices in childhood Participant B suggests that the association of women's voice with unwanted intrusion or demands on him led to an evaluation of the sound itself as aversive:

B: Actually, yes, the sound of voices, especially the sound of women's voices (right). That's what it was, that's what it was, 'cos I think I found women's voices quite kind of - intense is the wrong word - but very, whatever it was I was thinking at the time, there was nothing like a woman's voice to pull me out of my little world (right) and start telling me to do something or saying I should have done this, that or the other.

Similarly Participant G identified the absence of sound as anxiety provoking because of the association he has of sound and noise with the presence of people he trusts.

G:... I think frightening was being away from my parents or you know people I could trust and people made sounds... you know I associated sound with other people and felt less worried.

Participants describe a range of physical and feeling states associated with these problematic auditory experiences. These include irritation, discomfort, hurt, dislike, upset, tension, anxiety, aversion, fear, goosepimples, or shock reflecting variation in the way in which and in the degree to which different sounds were felt to be aversive. Participant G and Participant B both suggest a 'mental' basis to the discomfort and pain associated with loud sound. Participant G contrasts normal physical earache with the painful impact of certain sounds:

G: Umm, it's different - not like an earache. I've had infections in my ears and I think that's different. I suppose it's more internal perhaps in my head where my brain is, this hearing sound... because it's such a



shock that it sort of hurts inside and it seems too loud about where my eardrums are compared to ordinary sound.

Participants behavioural responses to these aversive experiences included crying and other signs of upset, fingers/hands over ears, running, escape and avoidance of the situation.

F: Very tense, yea, sort of, errr probably when I was young I cried a lot and that happened sort of, it made me go very tense I think.

G: At first when I was younger I would just sort of put my hands in my ears and try to get away... run away from it because it seemed too loud (yes)... I mean, I just wanted to get away because I suppose because I didn't like it and it was uncomfortable so I wanted to just get away from it.

B: Try to avoid being there. Well, I might have used any strategy I could think of as long as it fulfilled the motive which was not to be there.

Participant B suggests that repetitive or stereotypic behaviours were helpful in dealing with unpleasant sound sensitivity:

B:... sometimes I put my fingers in my ears and hum at the same time... cos I mean if I want, if it's visual I can just ummm put my hand in front of my eyes, to stop it coming in, but if it's auditory it's slightly more difficult. If it's smell I can just stop breathing...or try to breathe as little as possible... As for sounds, the only way you can really block a sound out is by, yea, fingers in your ears and make a noise of your own.

Participant accounts suggest considerable variation between individuals in the impact of these problematic experiences on their lives and social functioning. The impact of the aversive experience was in some situations



circumscribed and limited to the immediate situation. Participant F's dislike of certain vehicle noises for example did not interfere with his life:

F: It wasn't that big a problem, I just really didn't like it but if I had, if I was going on a car journey, then I'd go on a car journey (ahah), because we were probably going somewhere fun like a farm or... I could live with it, yea

However, for others these aversive experiences led to anticipatory fear and anxiety. Participant B for example describes the intrusion of thoughts about aversive sound occurring as producing quite high levels of anxiety which he felt might have been a bigger problem than the actual experience of the sound itself:

B: Yes, a high level of anxiety when, it was just like the thought of one of these things happening

These unpleasant hypersensitivities had a wider and generalised impact for Participant G. His dislike of loud sound was perceived by him to have resulted in restricted social opportunities with peers as he avoided social situations in which loud music might be played:

G: Umm, in certain ways, yes. Not liking loud music for instance made it difficult for me to get on with other people of my own age who being very much into pop music they liked to have it on quite loud... I think that's caused quite a problem, it just means I've got less in common with people to talk about.

He suggests that this aspect of his sensory-perceptual experience has become very much part of his personal identity, accepted by his family as an idiosyncratic characteristic and also as a source of affectionate teasing:

B:...Certainly I very rarely have things [music] on loud at all. Sometimes I just do it as a joke to my parents because I know other people's parents are always telling them to turn their music down and

so as a joke I'll turn something up loud until I get told to turn it down but it's only as a friendly family joke and I sort of know that.

Participants accounts suggest that the aversive experience of sounds as 'too loud' was a bigger problem in childhood. Participant F, now in middle adolescence, indicates that he no longer experiences vehicle sounds as too loud.

\*R: Is it still like that for you?

F: Not really, no, I sort of, no, not really.

\*R: Has it got less as you've got older?

F: Yes.

Participant G suggests that learning and increasing ability to make sense of and predict events has played a significant role in ameliorating his problematic reactions to sound.

G:.... Firstly as I got older, I was able to recognise more signs so was able to place them quicker or to be expecting them to happen anyway and so that become much less of a problem, obviously when I was very young and was curious about everything, everything would be sort of unexpected but now much less so. But I think there were a large number of sounds that were sort of unpleasant in some way because I found them too loud or you know didn't like them in some way when I was younger.

Participant C suggests that a process of familiarisation or desensitisation as he got older helped him to overcome the aversive impact of specific sounds:

C: Umm, sometime whilst I was growing up... I'd go into the garden and got used to them. And obviously at school I was using the drill during CDT....

Participant G suggests also that his 'exceptional hearing' has become somewhat diminished and that his tolerance of loud sound has improved:

G:... I used to have a very acute sense of hearing umm you know wherever I was in the house I could usually hear what was going on and that's slightly decreased...

G: Umm, I don't like very loud sounds, I mean when I was younger I didn't used to like even hearing music if it was turned up too loud because I had quite a good sense of hearing...

Despite an attenuation in problematic experiences of sound however, Participant G still experiences the discomfort of certain sounds as too loud.. He suggests however, that he is now much better at managing his reaction to them in a more socially acceptable way.

G:...I think I'm just more able to hide it now, I mean I now wouldn't go round with my hands over my ears 'cos I think that would make me stand out like something I might have done in the past but it sort of, I don't think as they become more familiar, I still don't like them.

His account highlights a danger in assuming that an absence of obvious behavioural reactions is indicative of a problem-free experience.

G: I think like much things, it was much bigger before I learned to control it in order to sort of fit in 'cos I mean things like that would make me stand out a lot which is obviously what I was trying to avoid. (yes, yes) So perhaps I now feel the same inside but bottle it up a bit more.

Participant B and Participant G's accounts make it clear that they are aware of how certain childhood behavioural responses to loud sounds (e.g. putting fingers in ears) were perceived as odd or indeed misinterpreted by others.

### **Perseveration**

This category refers to participants descriptions of a perseverative or 'repeating' quality to the experience of certain sounds and a similar tendency

in relation to thought where thoughts 'stick' both of which are described as impacting on sensory-perceptual experience.

At a physical stimulus level certain sounds are described as echoing, ringing or reverberating. This is described by a number of participants as a factor in problematic experiences with sound particularly those that are experienced as too loud or aversive in some way. Participant G in describing his reaction to loud shrill sounds such as fire alarms or train whistles describes it thus:

G:...something like a fire alarm that sorts of keeps going or just a sound that I'm sort of close to, a train whistle or something, often sounds too loud to me, I have to put my hands over my ears 'cos it (OK) goes sort of very loud and I can still hear it after it's finished....I'll sort of hear the ringing in my ears, a repeat of the same sound getting less and less loud as it takes time to die away.

Participant B makes it clear that this echoing is of a different quality to the physical echoing of sound:

B: Umm, it's not that I actually physically heard them echoing or anything like that but I think mentally I did. They'd kind of like, it's as if anything, any stimuli that actually went into my sensory buffer at all would stay there for longer.

In addition Participant G suggests a process where this reverberation leads to other negative effects of loud sound such as a drowning out of all other sounds:

G: Umm, well, when the thing was going, it sort of, it hurts my ears and I can't hear anything else, people who are talking, sort of the best example is at school after we have fire practices I can't hear anything anyone ever says while the fire, I mean the school bell, which is the same thing, that goes between lessons, (right) and that'll then depending on how long it's been going on, if it's just sort of gone of briefly to signal that whatever the first lesson has

ended, I'll sort of still hear the ringing in my ears, a repeat of the same sound getting less and less loud as it takes time to die away.

G:... if it was loud it would drown out things that other people could hear and it would just seem to sort of leave my ears hurting for a bit

This ringing or echoing may not be confined to actual physical sounds but may occur even where sound is imagined: Participant E recalls an experience in relation to nightmares where frightening sound continued to ring in his ears after he had woken up:

E: When I was having these nightmares I told you about before (yes, yes) with the big crows, they would have made kind of mechanical sounds when they flapped their wings (oh, I see) and that used to frighten me and often I was waking in the morning and I could still hear it ringing in my ears and it used to make me feel frightened.

Participant B also describes a perseverative tendency in relation to thoughts. Thoughts would stick in his mind and become difficult to dislodge so that to some extent thinking about an aversive sound or event could be more aversive than the event itself:

B: I was very kind of ummm, I would avoid it [sound of blunt pencil] like, yea, I had a strong aversion to it but when it actually happened I'm not sure how unpleasant it, I suppose once it was over... I don't know, it was just that sometimes it was hard to get the noise out of my head. When something, if something, yea, whatever thoughts I had at any time would tend to stick, it would be quite difficult to get any one thought out of my head and because of that it was quite difficult to make room for new thoughts to come in.

Participant B identifies this perseverative tendency as contributing to difficulties in concentration as well as his hyper-reactivity to certain stimuli:

B: Because I couldn't concentrate a lot of the time...maybe it's because I just used to daydream, maybe it's because whatever thoughts were in my mind at the time I couldn't really get rid of and because of that I couldn't make room for new thoughts to come in....That's also, I mean that's why I used to have this increased reaction to certain sounds and certain stimuli 'cos once they happened they remained in my mind for longer than they would with an ordinary child...Mental repercussions carrying on for a long time.

This bias or tendency may also exacerbate the impact of certain distracting sounds or thoughts in that once attention has caught by these, participants describe a difficulty in letting go or switching attention back to the original focus. This was indicated earlier in Participant G's description of the distracting impact of unfamiliar or unexpected sounds:

G: I'll stop and listen to it and have to think or maybe ask someone else 'what's that?' and often be quite unable to do anything until I have sorted out exactly what it is.

This perseverative bias may also be conceptualised as contributing towards the experience of not hearing or registering sound which was previously described where participants were intensely absorbed in one train of thought or activity activity:

G: Yes, if I'm focusing on a thing very much, I can completely...it's hard to come back as it were to everything else.

Thus this perseverative tendency may contribute at a number of levels to the experience of certain sounds as unpleasant, aversive or distracting: the disturbing or reverberating effect of problematic, loud or shrill sounds may be experienced as extended or magnified; and in addition it may be difficult to switch thoughts or attention from this unpleasant experience to a new, less aversive attentional focus.

In addition, this perseverative tendency is conceptualised as interfering with the efficient processing of incoming auditory information either because it is not heard (drowned out) or because it results in inflexibility which impairs efficient switching of attention between auditory events. As a consequence participants may miss out on relevant auditory information which is critical to making sense of and predicting events within their environments.

### **A-social, sensory world**

This category refers to an experience of the world which is primarily physical or sensory-based. Participants descriptions suggest an experience of the world in which awareness is primarily centered on the sensory or physical attributes of the environment and events within it. This has the quality of a naive or developmentally young view of the world: a world in which auditory events are a source of intense curiosity, wonder or pleasure with interest and exploration primarily driven at this level and not in a shared social experience.

Participant B describes an intense childhood focus on and exploration of the sound of rain:

B: Umm, I don't know, I don't think I really drew them to people's attention. I suppose if it was some hissing noise like traffic in the rain, and I could hear music as the traffic went past, other people said they couldn't hear any music in it, that was because they weren't listening for it, or at least not to the same extent as I was! But as I say, in the sound of traffic, you can hear anything you want.

Participant E in describing a childhood fascination with the sound and feel of satin explicitly refers to a preoccupation with sensory-based activity and detail at the expense of all other aspects of the environment including people:



E: I liked the sound and I liked the feel of it [rubbing satin]... and I remember one time when I went to a party of one of my mother's friends, her daughter was having a party, and she was called (Name) (right)... Anyway, it was her birthday party and I didn't seem to join in the dancing, the community games too much, but one of the girls had a dress with satin, part of it with satin on and I kept doing that [rubbing] with that as well! Which come to think of it was probably a bit aggravating.... Yes, [interest in] the things rather than the people.

There is a strong sense in which this is a non-reflective and a-social experience of the world: an 'in the moment' awareness in which there is an absence of a search for meanings and connection, and an absence of reflection on experience other than at a very basic level (e.g. association).

F:... I don't know, when cars pull up on the gravel, that's a sort of strange feeling, I always know somebody's here.

Participants descriptions suggest an absence of shared social understanding which contributes to a naive sense of wonder at what might, by others, be considered common experiences:

D: Well, sometimes I get distracted by other people's voices, where they're like talking in their own conversations, for some reason grab my attention...(right). I don't know why.... You know, I'm not talking to anyone, it just grabs my attention for some reason, someone else's conversation.

F: Well, I mean, certain music err makes me feel sort of strange,...it makes me feel a very, certain way, sort of it's the same with films actually, certain films make me feel um a very definite way, like they make me feel like they do in the films which is very strange, I don't know why.



Participant B's earlier description of the associational basis of his dislike of women's voices suggests an experience in which 'voice' is disembodied from its wider interpersonal and social context:

B: ... I think I found women's voices quite kind of, - intense is the wrong word- but whatever it was I was thinking at the time, there was nothing like a woman's voice to pull me out of my little world and start telling me to do something or saying I should have done this, that or the other.

This conceptualisation of an immersion in the physical or sensory aspects of events giving rise to 'associational learning' is also suggested by the description previously by Participant G of his dislike of silence and the comforting effect of repetitive sound because of the association of sound with the presence of people he trusts:

G: ... I don't think I ever liked silence very much, I was always uncomfortable in silence early. As a child, I liked either someone talking or some sound in the room, perhaps especially repetitive sound, (right), like sort of just banging on something or knocking two stones together that would always be there... I think frightening was being away from my parents or you know people I could trust and people made sounds... you know I associated sound with other people and felt less worried

Participants descriptions suggest a sense in which sensory and semantic processing may be separated. In describing the effect of becoming aware of outside sound when intently absorbed in an activity Participant D distinguishes between hearing at a sensory level and full 'attending' or registering:

D: No, I hear it, it's just that I don't realise that I should be paying attention to it.

Participant B alludes to a similar process which resulted in him 'missing' relevant sounds which others heard and which might have helped him predict events around him:

B: Maybe the sound of doors opening and closing 'cos that's relevant to what's about to happen next I suppose. They'd know when someone had just got in the house, but then I suppose so did I to an extent although I wasn't always concentrating on the right things.

Participant B makes a similar distinction in relation to the processing of speech:

B: I think maybe people were, used to respond quicker, especially in conversation. Other people seemed to respond very quickly in conversation, they would have heard meaning before I did. It took me a while to interpret what people said and put it into some kind of semantic code.

### **Concrete world view**

This category refers to a framework for interpreting and responding to the world which is rooted in the physical and concrete, eschewing abstract, social or reflexive interpretations or strategies. The physical or sensory experience-based experience described by participants is associated with a primarily concrete (as opposed to a reflective, cognitive or social) way of interpreting, managing and responding to events around them.

'Mental' events or thoughts may be ascribed a 'physical' interpretation. As previously described, Participant G rather than using mentalistic terminology describes 'hearing' his thoughts in terms similar to 'real' sounds. He enacts in a physical form cognitive efforts to attend to or 'listen' to these thoughts:

G: Mmm, I think if I jaw-drop slightly, I don't know I think there's something in your head that opens up or shuts down, that it's almost as if that puts a slight buzzing in my ears I think.... Umm, something I

sort of think mentally, but then sort of move my mouth slightly. I mean I'm not quite sure what it does but it's like that, it means that I can hear my internal thought clearer and it shuts out outer thoughts [sounds] slightly more.... It's just that slightly concentrating I think about it and hear a sort of slight click in my ears and that helps me to concentrate, focus I think.... it's almost like switching off (Ummm). I do it if I'm trying to think something in my head and I can't hear properly, I can't hear myself think, because other people are talking, then I'll do that and that helps me hear my own internal thought clearer.

Participant D's account of and reaction to 'mishearing' his name suggests a lack of reflection on experience which leads to an over-physical view and response to events:

D: ... Especially one of the problems is that I can hear people saying my name and I'm turning round to see what they want and there's no-one there, it doesn't seem to happen that often but it's weird.... The main problem with that now is that sometimes when people do say my name I ignore them.

Participants accounts suggest that sensory or attentional 'blocking' or physical escape from the situation is used as a means of dealing with a range of unwanted events or situations including unpleasant sensory events and unwanted social demands and experiences. Participant B above described a role for repetitive humming used in conjunction with covering the ears as a way of dealing with unwanted sound. Similarly Participant G describes physical strategies to deal with aversive sound:

B: At first when I was younger, I would just sort of put my hands in my ears and try to get away... run away from it [loud unexpected sound which left his ears hurting] because it seemed too loud ,(yes), so perhaps I've got a slightly higher tolerance now. I mean, I just wanted to get away because I suppose I didn't like it and it was uncomfortable so I just wanted to get away from it.

Participant B describes using repetitive humming as a blocking strategy in a number of situations:

B: Umm, some teacher coming up to me with a big piece of work and saying I had to do it, when in actual fact I didn't understand any of it, or asking me why didn't I this, that and the other and I might have thought I had done or....

Sometimes when my sister used to talk to me (!), sometimes I used to get very annoyed with my sister, as brothers and sisters do (yes) but in my case I think it was a bit extreme at times, sometimes it was unwarranted. ... A lot of the time, a lot of the time it was just everything about her I used to find irritating, especially the sound, especially when, especially her voice.

#### **Fascinations(sound)**

This category relates to participants descriptions of sound as a source of enjoyment, comfort or fascination. Echoing a sense of immersion in a sensory based world participants accounts indicate that auditory events were a source of considerable pleasure in childhood.

Engaging in repetitive or stereotypic behaviours which may serve a function of blocking out unwanted sound or events in one context may in another context be employed solely for the sensory based pleasure which they generated:

B: Sometimes I'd do it [repetitive humming with fingers in ears] for no reasons at all except that I liked the feel of it and the sound of it.

In addition all participants described some type of fascination with sound or sounds in childhood. A number of specific attributes, either singly or in combination were identified by individual participants as underlying the appeal of these pleasurable sounds.

### *Repetitiveness*

Participants suggest that a comfort with repetition or sameness is one significant factor in the appeal of certain sounds and a range of these sounds were identified by participants as sources of pleasure or enjoyment;

F: Repetitive noises now I come to think of it. Like when I was little I had a little ummm, what was it, a little merry-go-round that sort of had little people in that made a sound when you wound it up and I sort of went to sleep listening to that. I think quite repetitive noises that carried on going were quite sort of relaxing...

### *Intellectually based pleasure or fascination*

B: Actually I used to spend a lot of time mucking around with the computer making all kinds of, piecing beeps together and making sounds that way, a lot of sounds I made on the computer used to fascinate me... I think it was harmonic simplicity in a way, I think almost the more kind of, more fundamental, the physics behind the noise was, I don't know.

F: ...beeping I think... again sort of any repetitive beeping noise I like...It's electronic, anything to do with electrical equipment because I'm sort of very technical, like sort of.. (ahah, ahah)...It's investigating, ummm, it makes me want to investigate that noise and see where it's coming from.

### *Predictability*

While an intellectual fascination with the way a spinning coin managed to stay upright was identified by Participant E as underlying his childhood obsession with spinning coins, his account of the enjoyment of the 'juddering'

sound of the coin as it fell suggests that at least part of the pleasure resulted from the inevitability or predictability of the event:

E: Yes, I used to like things like getting a coin and spinning it and watching it spin until it virtually came down.... Just the idea that something is just balanced on its edge and still manages to stay up.... Yes, and the sound of it eventually falling down, which it always did.... I don't know, I was just a bit fascinated with it.

### *Soft sounds*

'Softness' was described as one element in the appeal of certain repetitive sounds such as the sound of rivers, the sea, fountains and also in the appeal of quiet, barely audible sounds such as the sound of satin rubbing.

Participant F's enjoyment of soft quiet voices suggests a separation of the sensory from its social and emotional context which resonates with earlier descriptions of a sensory based world:

F: Oh even now like if I'm going to the optician, she talks really softly and close and quietly and I like that for some strange reason. I don't know why. Anybody who talks softly and slowly and quietly I sort of like the sound of that. I might not like the person! but sort of the sound is really sort of, I don't know what it does but I like it.

### *Sounds associated with obsessional interest*

Participants C, F and E describe a fascination with sounds associated with their wider obsessional interests. Participant E's ability to recall the details of a record of train noises which he had as a child is suggestive of considerable pleasure and immersion in this activity:

E: Oh, I used to like trains. At one point as a kid I had a record of train noises which I still remember now - a steam engine shunting, a steam journey and a diesel journey -... I remember enjoying them...

*Sounds associated with relaxation or pleasant situations*

G: I like the sound of things burning, the slight crackly sound of the fire, possibly 'cos I've been comfortable when I've been somewhere with a fireplace and I've been warm and felt better, that sound I like.

*Sound as part of a multi-sensory experience*

It is also clear from participants accounts that enjoyment of the sound of particular events or objects was in many cases part of a much wider multi-sensory or intellectually intriguing experience e.g. E's fascination with the spinning coin above or his childhood fascination with satin:

E:..... I think maybe, I recall when I used to be a kid I always had a satin ribbon on my eiderdown (right) and I always used to do this with it (oh, right, rub it between your fingers like that) yes, and I always used to go to sleep rubbing it between my fingers like this....I liked the sound and I liked the feel of it..

Participant F's description of his enjoyment of a particular merry-go-round suggests difficulties in analysing and articulating modality specific elements in what is essentially a multisensory based experience:

F: ...I mean the noise was, I don't know what it was, but it was repetitive (uhum) and it had different coloured swings on it. The main body was all the same colour but then it had different coloured things going round and the pattern of people in it going round. I don't know what I liked about it but I think it was the sound and the colours and the spinning... I'm not sure really.



*Impact of fascinations*

Participants accounts suggest variation in the extent to which specific sounds were actively sought out or simply enjoyed opportunistically and this varied across individuals and within individuals across different sounds and situations. Participant B for example suggests that his childhood fascination with computer generated noises led him to seek out opportunities to pursue these while his enjoyment of the sound of the rain or sea was opportunistic. Participant E suggests that he would have sought out coins to spin and engaged in this activity for considerable periods while Participant F's descriptions suggests a much less intense focus:

E: I think I might actually find something to spin.

F: No, no, I really don't like going out of my way to do anything really!... if I hear them it's all right.

A number of participants describe a sense of loss or anger at being disturbed or interrupted when they are listening to or immersed in these pleasant sounds.

G: Yes, it makes me very sort of angry when someone interrupts me when I'm listening to something that I want to listen to.

However, there is a more general sense in which Participant G describes 'being interrupted' when actively engaged in any listening activity as intrusive which again resonates with the conceptualisation of a physical or sensory based world view:

G: Umm, I'm trying to think..... err, when I'm sort of really want to listen to something that I like, whatever it is, whether I want to hear or whether there's just someone talking or if I was listening to something like a bird or something outside, I would feel ang... yes, if I was listening to a bird that I thought was



interesting that made a nice call or something and I found that enjoyable, if someone tried to speak to me, I'd perhaps be more likely to snap back at them unexpectedly in response you know because I'd be upset that I'd been disturbed in what I was doing.... I suppose it's a sense of loss I suppose - I'm doing something I want to do and then suddenly it's stopped and so I suppose quite selfishly I'm angry with the person or whatever who's caused either the sound to be turned off, if it's the noise I'm listening to, it's then been turned off, or if they speak to me or disturbs it or startles it or means I can't hear any more.

## *Vision*

### **A-social sensory world**

This category refers to participant descriptions of a primary orientation of awareness and interest in the physical and sensory as opposed to the social world. Intellectual interest and exploration are described as being grounded in the physical rather than the social or meaning based world of ideas.

Participant B recalls his earliest memory and curiosity as centered on a sensory image:

B: Actually, there's even something before that but it [first memory] doesn't actually involve any people as such. I remember darkness (oh, right) with a red diamond shape in the top right-hand corner or something - I can't remember - a kind of dynamic diamond shape,... Yes, it was quite pleasant - it wasn't unpleasant. I was curious I think, curious was always, actually it's an emotion I've experienced many times.

Participant B describes a childhood visual world experience which was embedded in the physical environment. He describes a largely a-social experience in which interest and attention centered on the detail of the physical and sensory environment. He contrasts this with the 'normal' orientation to people and the social world:

B: Umm, Yes, oh yes, [awareness of detail of which others seemed unaware] ummm, the patterns on people's pullovers for a start, the carpet, the rug. My field of vision was often around carpets and that kind of thing and my, and all the angles and the acoustics of the room and all the kind of physical environment, the colours, the designs and everything, that used to register quite a lot in me whereas with other people I suppose their fields of, their visual attention was much more

focused on each other and on the people rather than on the actual environment.

B: Umm... I think I used to be a lot more, I used to be a lot more interested in shapes and forms and kind of like cuboid-like forms and stuff rather than faces. (Right). I used to like, yea, patterns I used to see and the patterns on people's pullovers was a recurring kind of... I mean I noticed that all over.

Participant F describes a sense of intense childhood excitement in the visual and in concrete visio-spatial achievement:

F: Everything was really exciting when I was a child. I don't know really.... I mean, everything really was sort of exciting.. errr especially when I was putting the puzzles together, I liked seeing the picture come together and things.

Participants refer in different ways to a link between their social impairment and this attentional orientation to the sensory and physical environment although the exact nature of the relationship remains unclear.

Participant E and F describe difficulty in looking at people when talking to them and the tendency therefore to look elsewhere. Participant F describes a tendency then to be distracted by the shape or shininess of objects:

E: I think even until I was 16, I couldn't look somebody straight in the eye very easily. Often I was talking to somebody and I'd look 45 degrees from them, like I might be talking to you and looking like this[indicates looking past interviewer].... I didn't feel comfortable looking somebody in the eye.

F: ... when I talk to someone anyway I normally don't look at them because I find that really hard to do but so I just look at anything else, like I'm doing now of course! But ummm I don't know really, the sort of smallest thing [attracts my attention] for some strange reason or the table leg, I don't know why.

Despite this a-social orientation it is clear nevertheless from participants accounts that there was an awareness of people and an attachment to trusted adults who could assist participants in negotiating the vagaries of this sensory world. Participant B indicates that having people around who understood his fear of butterflies served as allies in avoiding the feared situation:

\* R: How did you do that [avoid bubbles, butterflies, moths]?

B: Ummm, I suppose by having people around me who understood.

### **Orientation to repetition and pattern**

A key aspect of this orientation to the physical and sensory world are participants' descriptions of an attentional orientation to repetitive, predictable pattern and symmetry within the visual field. Participants describe being drawn to or fascinated by visual events that contain these elements.

B: Umm, umm, I think it [drawn to] was mainly, I think anything that contained some degree of repetition or symmetry in its form, anything that was kind of intellectually stimulating in the visual field.

F: Patterns umm.. I like patterns or symmetrical things or repetitive things (uhum, uhum) or.. errr... I like those masks, sort of that are symmetrical on both sides.... I like modern art, sort of straight lines, squares of colour and things like that, I've forgotten the artist's name now but he sort of draws big pictures with straight lines and colours and squares, I like that (uhum) I don't know why.

Characteristics of repetition, predictability, and dynamic pattern are also present in other visual fascinations described by participants, for example rain, fires, flickering computer screens, waterfalls, spinning tops/ objects

B: Mmm, it's recurring repetitive patterns, it's just that repetition I think. That's why, I suppose that's why I might have used to like watching spinning tops or why I liked watching waves going past, water, that kind of thing. It's predictable and it repeats.

D: Flickering things tend to [draw him in], like computer screens especially. Subconsciously what I do is sit in front of it and tend to sort of stare at it, see it flickering.

There is a strong sense from these accounts of a subjective experience of cognitive congruence or emotional pleasure in visual stimuli which possess these characteristics. Participant B describes as an adult a similar pleasure in mentally visualising scenes involving these sorts of visual events:

B: yea, I suppose I, I get a nice feeling if I think about waves in water, swimming pool of some kind and the waves are going up and down slowly, lapping against the side of the pool, and the side of the pool is kind of like a grid like formation, a pattern blues and greens and whites, a kind of zigzaggy pattern of the tiles on the side of the pool, and the smell of chlorine.

Parallel to this sense of congruence, participants describe a sense of dissonance or irritation where disruption of repetition, pattern or symmetry occurs within the visual environment.

Participant B describes a feeling of irritation at breaks in visual pattern and an intellectual drive to repair or restore the pattern to regularity:

B: I used to like, yea, patterns I used to see, I used to think about how they would fit together and the patterns on people's pullovers was a recurring kind of.... (uhum) I mean I noticed that all over, in everything I saw there was symmetry all over the place, yea, symmetry and repetition, and when I saw something that broke the symmetry or repetition of a certain pattern, I used to find it irritating and I used to be kind of.. it used to cause me almost to want to design another pattern to compensate and make it symmetrical again.

Participant E describes a similar drive to achieve a more pleasing sense of symmetry:

E:... I remember when I was a kid sometimes when I was talking to my father, I would, my eyes strayed away and I watched, I was looking at the pattern of cups on the place they were hung and wondered how I might arrange them differently.

R\*... So was that something to do with the pattern?

E: Yes, it was to do with the pattern. It's whether I can make it more symmetrical or more pleasing.

Once hooked into these visual events and the need to 'repair' them a number of participants describe a difficulty in disengaging from these stimuli. This in turn distracts from other events and sources of information:

B: Yea, I would need to reform it somehow so I would keep staring at this pattern and I just wouldn't let it go until I could, until I could see a way in which the lines could be moved to get it back together again. This often used to distract me from relevant information like instructions someone was giving me at the time.

Participant E recalls that while he might be slightly bothered by a mistake in a pattern the main problem arose in relation to negative social consequences arising from his tendency to be drawn to or distracted by these sorts of stimuli:

E: Well it didn't bother me but it sometimes bothered other people that I didn't seem to be listening to them. Even if maybe I was.... The main problem was that I was looking at that instead of looking at them.

Participant B also described negative social consequences:

B: ... I suppose it's mildly unpleasant when you can't work out how it should fit together and then when you think of something which should make it work, then it's mildly pleasant and eventually whosoever jumper it was would turn round and ask me what I was looking at.

However, Participant F describes the impact of disrupted pattern as less distracting - irregularities that did not meet with his approval did not engage his interest and were therefore ignored:

\*R: Would it bother you if the pattern was broken? If umm...

F: If I liked it [break in pattern], then no not really. If I liked the way the pattern was broken, I think it would be all right, but if it was, if I didn't agree with the way it had been broken or if it was didn't look right then I wouldn't spend much time looking at it.

Lack of predictability and suddenness of movement, alongside changing symmetry, are also identified as elements which contribute towards Participant B's fear of butterflies and bubbles:

B: I was afraid of bubbles (ah) 'specially when they clustered together (right) - terrified in fact (OK). And I was afraid of butterflies and moths. ... Butterflies are very unpredictable, they move very suddenly, first they're there and then they've gone off, and their wings kind of fold, and umm I found that scarier, the symmetry as well I suppose, there's something about the symmetry that I found scary. Bubbles - I found that when they cluster together they're unpredictable and I couldn't work out what they were going to do next.

The absence of symmetry is identified by Participant F as underlying his dislike of looking at or entering old buildings;

F: Errr. I think old buildings, I still don't like going into, I mean I don't like going sort of, I don't like the look of them, the old, I like new huge skyscrapers with windows made up of glass and things. ... I don't know, there's no struc.. there's no sort of, it's not symmetrical..

#### **Negative case requires comment**

However, unlike Participants B, E and F, Participant G does not report an attentional bias towards or interest in non-dynamic repetition and pattern. On the contrary, Participant G reports a general lack of interest in shape and pattern and describes as effortful and tiring attempts to 'work out' intricately drawn lines or pattern.

G: I like something to be geometric rather than abstract but looking at something that's very organised gives me a sort of headache in the intensity that it's been drawn so having to concentrate on something that's like a shape, that's been very intricately drawn, that's like made of lots of straight lines, then that sort of geometric pattern I don't like, a sort of line drawing that's made of all sorts of straight things, or having to follow it to work out where it starts and ends, I don't like that sort of thing.... It's the effort, I find it hard to work out and I have to look and I sort of get the headache of just sort of feeling that it's very hard and tiring but patterns have never interested me at all. (Right) I



hardly ever register them. When you look at those 3D pictures that are hidden within things, I can never see them inside another pattern, that sort of thing.

Nevertheless in keeping with other participants he reports an enjoyment of specific activities and visual events which are dynamic manifestations of these elements of repetitive pattern e.g. spinning tops or other spinning objects.

### **Pattern and Intense Absorption**

Repetition, predictability and/or dynamic pattern characterise many of the visual events that participants describe themselves as being drawn to or fascinated by. Participants describe a process of intense absorption in these events which impacts on awareness of the wider environment around them.

Participant B describes a pleasurable intense absorption akin to a hypnotic effect which arises as a result of getting drawn into dynamic pattern;

B: Yes, it's quite pleasant, quite pleasant, it's like umm, because you can lose yourself I suppose and it's not kind of like, it's almost like it switches you off from...

B: Yes, very much. Umm... Mmm. It's almost like hypnotic in a way, you get drawn into a dynamic pattern of some kind or anything that's kind of dynamic in the way it behaves, predictable, 'cos a spinning top is fairly predictable (uhum) and a waterfall is predictable and I suppose, any predictable kind of sequence or pattern that was dynamic I used to get quite drawn into, I could stare into it for ages, like you can stare into the remaining, the remains of a camp fire for quite a long time (Right, OK), you can almost get lost in the flames.

Participant F describes a dissociative type experience which arises from a focus on telegraph poles, trees or people as he speeds past in a car:

F: If I'm driving I like watching things go past. I've just thought of that actually, I do sort of focus in on telegraph poles, very strange, umm. ... Or anything really, trees and people walking past, I like watching as they go past and things... [I feel] very relaxed, sort of involved in the moment as it... I



prefer to talk to them [parents] whilst looking out the window, I'm not sort of there really, sort of telling them what they want to hear.

Participant E also recalls watching lamp posts as he went by in the car but describes this in more neutral terms:

E: Yes, I remember looking at the lamp posts as we went by in the car. and watching them. ... it was just something I focused on.

There is a sense in which these participants describe, without effortful management on their part a gradual involuntary entrapment by these stimuli

B: I'm not really sure how it would begin - I suppose I'd just see something that caught my eye and gradually become entranced by it.

These descriptions suggest a change in awareness or consciousness which may be similar to the experience of intense daydreaming. Participants descriptions suggest an experience of awareness having been somewhere other than in the 'real world' and a sense of difficulty in switching awareness between these 'worlds'. Participant D describes this experience in terms of an attentional process:

D: ... it's just sometimes difficult to like come back to the real world. ... it [another person interfering] would just sort of like get my attention back to everything else.

Participants' descriptions suggest variation in the extent to which these experiences were sought out or under volitional control.

Participant B recalls that this effect was pleasurable but an experience which was enjoyed opportunistically rather than actively sought out:

B: It's not something I used to actively seek out but when it happened it was nice.

Participant D describes a similar effect of intense absorption from watching spinning objects but describes it in more neutral terms:

D: It just seemed you know to draw me in a little, like 'em flashing lights.... it's just something that I stared at for a long time, I don't know why.... it was sort of everything else seemed to blur out.

Participant G's account of the enjoyment of spinning tops however, suggests an effect which is more actively pursued and functional - a means of achieving both a sense of relaxation and a sense of power and control in a context where 'seeing' requires active concentration:

G: Umm, we had a.., I think we had one of those toys that you sort of pumped a handle that would make it spin round and that made a noise as well, as well as spinning, and it's the same with, now, things spinning like pennies on a table or spinning a little top made of paper that spins round and round. ummm I think I find it relaxing to my eyes cos I can sort of go out of focus. but it's quite a strain what with everything else having to concentrate on seeing, focusing on things as well. What with all the other things I have to do but it's nice sort of just looking in blackness would relax the eyes, looking at something like that at the same time as hearing a sound and perhaps the feeling of being in control if I'm the one who started it spinning, it's a sort of power feeling I suppose, so perhaps that as well.

A number of participants describe the impact of being interrupted or disturbed when in this state of absorption. Again all allude to a change in consciousness or awareness as a consequence of this disturbance. Participant B recalls the strongly aversive impact of being disturbed when immersed in this activity or hypnotic experience:

B: ... like being woken up with a bucket of cold water.... Yea, I mean, imagine you're having a really nice dream and then suddenly someone, umm someone pulls the planks out from under your bunk bed! It's very sudden! you don't expect it at all.

R\* Would it have made you upset?

B: Umm, possibly, possibly-possibly upset.

Again for Participant D the effect of being disturbed is described as less dramatic and less aversive:

D: No, it would just sort of like get my attention back to everything else. ... Not really [bothered if interrupted], it's just like I've woken up.

Participants describe being particularly prone to entrapment by these sorts of stimuli when not actively engaged in or concentrating on other tasks or activities. Participant D while initially reporting that distraction by these stimuli seemed random, went on to suggest that entrapment was more likely in the absence of active involvement in other activities:

D: I suppose it might do [get drawn into spinning tape], if I was looking at it for a long time and I wasn't like concentrating on doing something else.

D: It's only when I sort of stare at it, it just happens like when I'm not particularly doing anything else.

D: I wouldn't do it [drawn to fires] if I was sort of busy doing something else. I wouldn't just stop, but if I was just sitting down in the room, not doing anything, I might.

Participant B suggests that conscious and effortful management is required in order to disengage or prevent himself being drawn into repetitive and predictable patterns and shapes, a skill which has become more efficient as he's got older:

B: no, I have I think a sufficient degree of control over it [tendency to get drawn into patterns] now. I umm, I almost consciously tell myself to let go.... I think I'm quite good at stopping myself now.

Despite a strong urge, Participant B learned to control or manage the urge to interfere where others had produced a less than perfect pattern:

B: And sequences, and patterns which didn't fit together in a regular way (right) which - interrupted things. If someone drew something and the pattern was interrupted in some way, I had an overwhelming temptation to go along and correct it for them and make it regular and symmetrical again. (Right, right, OK) but I wouldn't, I don't...

### **Preferring the familiar**

Alongside this orientation to repetitive, predictable or symmetrical stimuli a number of participants describe a more general preference for the familiar within the visual

environment. This includes a preference for visual events which the participant has previously seen and a reluctance to accept change within the visual environment.

Participant G describes a general preference for visual events which are familiar:

G: I like familiar things, I mean I prefer things that are black and white and colourless than things that are full of colour. But generally I prefer something that I've seen before than something that I haven't seen.

Participant E recalls an incident suggestive of a strong childhood dislike of change in the visual environment:

E: There was the time when, which my mum might have told you about, when she had a wall which had been painted on it before and she decided to repaint it green and I well, I was upset about that, and to appease me she left one little corner on the top right hand which was left orange and I used to call it a budgerigar, I don't know why. ... I must have been about three or four and she repainted it and she left that bit there. I think it was the change[that I disliked].

This preference for the familiar is described as a more pronounced feature in childhood which attenuates with age and effortful management. Participant B describes his efforts to overcome this orientation to sameness which he considers impinges negatively on his life. This has required determination and effort:

B: ... I feel kind of forced into looking for variety in things. I feel as if like if I don't keep trying to find variety and if I don't keep pushing myself out of these little things that I'm not going to get much further in life. I've got to keep, I've always got to be actively seeking new things - new ways of doing things.

As a result Participant B sees himself as much more adaptable and accepting of change in adulthood:

B: I think now I've actually reached a stage where I feel quite adaptable, I'll accept, I suppose I'll accept any kind of environment, more or less.

Similarly Participant E recalls how the difficulty in accepting change in his visual environment was no longer an issue in adolescence:

E: Of course next time she repainted it, I was well into my teens so I didn't mind.

### **Visual fascinations**

Participants also describe other visual interests or enjoyment of specific aspects of the visual environment which may be idiosyncratic to the individual.

Participants C and F both describe a particular enjoyment of lights. Participant C recalled pleasure in street lights, car lights and other types of light. His account suggests a simple aesthetic pleasure which has continued into his adulthood:

C: When I went out for a little walk at night near the river during the winter, I used to look at the lights in the distance.... I think it must have been seeing the lights in the distance[that I enjoyed]. Not all that far, just in the view....I liked, I just liked to look at them, street lights....oh, the different colours of the street lights.

C: ...well I've been, well I've stopped [in adulthood] to look at views of lights in the street.

Participant F specifies a liking for artificial as opposed to natural light:

F: I like things lit up, like ummm walking into a huge room and there're lots of lights all shining down and everything. I like that.... I don't like naturally lit rooms, I mean I prefer lights that are artificially

lit and things but I don't know why really.... I like any sort of light that's in the dark I think I like really... I especially like when it's dark outside and everything's light inside. I don't know, I think it's sort of, ummm... like it, it's a sense of warmth or something sort of thing...

Participant C also reports enjoyment in looking at straight lines and telegraph poles. His description suggests two elements to the appeal of these stimuli - a simple aesthetic pleasure, but on further exploration an element also of intellectual appeal:

C: Umm, straight lines, err, I like looking at lines when I'm measuring things and when I'm underlining titles. Err, I like looking at lines when I'm going on a train anywhere and I look at the railway lines from the railway station platform.

\*R: What makes them so interesting?

Mat:... Err lines are useful

C: ... I used to be interested in telegraph poles. I used to think why they dealt with the wires so high up and I used to be interested in the locations of each. ... I really liked to see them.

Similarly Participant E's account of a fascination with tiny leaves and insects which he observed in minute detail and for long periods in childhood, centers on an intellectually based curiosity about the insect world, a topic in which he later reports some continuing interest in adulthood.

E: Apart from trains I was also fascinated about insects. ... I was always hunting insects from when I was five or six... I liked to watch them and observe all the things they did.

Participant E describes an element of pretence in relation to his play with leaves which again arose from this intense interest in insects. Elements of imaginative play were not described by other participants in relation to visual fascinations.

E: Yes, I remember doing that [rubbing between his fingers] with leaves and I remember breaking leaves into pieces and I remember we used to have a whole load of box trees with little green leaves, and I used to often take little sections of stem with two leaves and get a few of them together and pretend they were insects with two wings.

One participant, Participant B indicated a reluctance to dissect the nature of the appeal of these events in too much detail with the implication that cognitive understanding or analysis might in some way undermine their pleasurable impact:

B: I don't know. If I was to explain it [pleasure in watching rain], it would probably break down. ... I'm not sure if it's something I want to question actually. I think I'd rather just {pause} yea...

While Participant G does not report particular pleasure in visual events other than dynamic pattern, he does describe an emotional attachment to small objects or 'treasures'. Loss of these objects may provoke an intense emotional reaction, leading to social difficulties:

G: 'Cos I can have been coping fine and then I might have dropped something out of my pocket that I'd been holding in my hand all the time and not able to live without, and I could then suddenly you know have a temper tantrum or something and they think why on earth is a 17 year old behaving like this. So I think that's the - it's fitting in I think is the biggest problem but I'm still working hard and it should get better.



## **Unpleasant Visual Events**

This category relates to participants' accounts of visual events other than those already described which idiosyncratically provoked a degree of displeasure, dislike or anxiety.

### *Sharp pointed objects*

Participant G's recall of a dislike of sharp pointed objects suggests a cognitively based but irrational anxiety around the danger of these objects:

G: Umm, sharp objects. Whenever I'd see a needle or a pin, as soon as I saw it I felt as though it was sort of sticking into my nose, the point end seemed to get closer and closer to me, so I disliked those intensely.

### *Dislike by Association*

Participant F describes how his appraisal of a visual object or event is influenced by the emotional context of the situation pertaining to it:

F: Errr..... errr..... ummm... not really. There was, if I didn't like the look of something, it wasn't because of what it looked like, it sort of felt like really that made me feel (right). It wasn't so much what it looked like. ... Ummm..... umm, I mean I could be looking at a really nice picture in a book or something I'd been reading, it could have been expressing something terrible like I don't know what though and ummm... I mean the picture, I mean looking at it would have been really nice (mmm) - trees, lakes and things - ummm, I'd have been reading the book and it could have been saying this was a setting for errr some mass murder (right) and the picture wouldn't, how can I say it, sort of the way I would feel would be different to what I was seeing so I would sort of rely on the feeling not the visual bit..



In addition to unpredictability and sudden movement Participant B suggests that there was in addition, underlying his fear of butterflies, the fear of actual physical contact.

B: I think one minute it would be perfectly still and the next the wings would start folding and then they'd come together and then it'd flutter off (right) umm, and you never knew where it would be next, you never knew, I mean I never knew from one minute to the next whether it would be in my face or something (right) and if there's anything, nothing could be possibly worse than actually, actually having contact with that butterfly (!! ) in some way.... Anything to avoid actually touching it.

Taken together with the dissonant impact of breaks in repetition, symmetry and pattern described above, these accounts indicate a significant range in terms of degree of unpleasantness arising from specific visual events. These range from the mildly dissonant feel of E's reaction to interrupted pattern to Participant B's terror when confronted with bubbles, butterflies or moths. For example Participant B's full-blown panic response to bubbles and butterflies in childhood led him to want to escape from or determinedly avoid these objects:

B: Yea, it was some kind of umm , it was as if the fear came from the stomach kind of (right), as if it was all kind of being pulled, my legs turned to jelly and ummm my stomach turned to jelly and I suppose I was getting ready to run really. It's the panic response isn't it, fight or flight and I chose flight. ... Anything to avoid getting into those situations!

Participant B suggests that a childhood lack of reflection on what is being experienced or 'in the moment' awareness contributed to the terror felt in the presence of butterflies:

B: Almost as if it would make the universe close in (right) I don't know, it's very difficult to actually describe. Whatever, I suppose,

umm, as a child whatever it is that's happening at that instant in time, whatever state of consciousness you're experiencing, it's almost as if that's the whole universe (right, OK) umm, I mean if there was a child in this room at the moment, quite a young child, or an older child who is autistic, sitting in this room at this moment, they could possibly umm, they could possibly feel, they could feel quite strongly or maybe even believe that, umm for a fraction of a second actually believe, that this room and the rain outside is the only thing in existence (right). Imagine if the only thing in existence is this butterfly that you're afraid of.

This immediate and powerful physical response contrasts sharply with the milder and more cerebral impact described earlier by Participant E in response to interrupted pattern.

Participants accounts do however, suggest that their reactions to these unpleasant events were circumscribed and limited to the situations in which these objects or events were actually present with no suggestion of any wider impact or anticipatory anxiety in their lives or behaviour.

B: Ummm, actually I'm not sure, ummm, I'm not sure if it was that much of a... it didn't really get in the way of anything much.

In general participants describe these reactions in the past tense and largely as childhood phenomenon. Where they persist they do so in a greatly attenuated form - Participant F's dislike of old buildings for example is not associated with fear and does not prevent him accessing old buildings. Participant B's fear of bubbles and butterflies is no longer a problem:

B: [Fear now] mildly, very mildly, but not really.

### **Distractibility**

This category refers to participants descriptions of visual distraction by the wider environment or a susceptibility to noticing visual events outside of

those at which they are looking directly. This susceptibility is felt to underlie a number of phenomena described by participants in recounting their visual experience.

Participant D describes an experience of being aware of and distracted by events in peripheral vision, visual events which may seem clearer or different than when viewed through central or foveal vision. There is a sense of wonder that events will look different when viewed out of the corner of the eye than when viewed centrally:

D: Sometimes things like look differently when I look out of the corner of my eye, especially the things that are flickering, I can see them flickering a lot clearer from the corner of my eye but when I look at them they're not, not visibly. Occasionally I can see it with fluorescent light but it's not really happening now (right)... It's different when I'm looking at straight at it than when I'm looking at something else.... It's just drawing my attention to looking at whatever it is (right) and then I always see that it's different and..

Participant D's description suggests some confusion which arises from this experience about the exact nature of visual events and describes how in the past this tendency to be aware of and distracted by events in peripheral vision led to misinterpretations or seeing things that weren't there::

D: Maybe, it's difficult to explain, I'm not sure whether these lights do flicker, I don't think they do, umm, no they don't, they don't flicker at all. (Uhum) They seem to pulsate slightly when I'm not looking directly, it's stopped now, I don't know why.

D: Occasionally [I] see things that are very far in peripheral vision like umm people usually. (Right) But I mean even if I turned slightly towards them, they're not there, well I don't really see that any more. I remember the comments that I was seeing ghosts. ... It didn't really scare me though.

Participant D describes this distraction by events in peripheral vision as a usual or common aspect of his visual experience:

D: All the time really. It's just one of the things that happens.

Participant F's description of his eyes 'playing tricks' on him suggests a similar process of distractibility and possible misinterpretation:

F: No, they still do. I mean I'm sitting and I see shadows of people and things and sort of very strange things walk past because when I was talking to you a few minutes ago I saw something whiz past the window, only very quickly. It could have been a bird or something, and I sort of saw it and anything that sort of goes past very quickly of just out of the corner of my eye, I see.

In addition participants describe certain visual stimuli as particularly distracting. In addition to being drawn to and distracted by repetition, predictability and pattern which has already been described, Participant F describes his attention tending towards shiny objects or jewelry, stimuli which he finds himself drawn to and which he finds visually pleasing;

F: Any situation, I mean any, anybody wearing like shiny jewelry sort of thing, I sort of look at that...

Participant G describes himself when actively concentrating as being prone to distraction by lights or bright or flashing stimuli:

G: Err, not [distracted] unless it was in the sense of lights. I mean I play chess sometimes and I don't see things that go on anywhere else because I'm not looking around... the sight of someone walking past doesn't sort of register but something to do with lights or sort of bright and flashing, it would...

Implicit in Participant D's account of visual fascination with flickering computer screens is the capacity to detect the rapid flickering on screen which suggests a level of hyper-acuity or heightened ability to detect these very rapid variations:

D: ... subconsciously what I do is sit in front of it and tend to sort of stare at it, see it flickering. ... It's not sort of very flashy, 'cos it's oscillating about fifty times a second, so sort of very quick varying in brightness.

Participant D suggests that this ability to detect rapid flickering occurs under conditions in which he is not actively engaged in other activities and he looks closely at the screen:

D: It's only when I sort of stare at it, it just happens like when I'm not particularly doing anything else.

Participant F identifies motivation as a factor which heightens his susceptibility to distraction:

F: If I like what I'm doing then yea, but like at school I really don't like what I'm doing I would be very easily distracted by anything.

### **Hypersensitivity**

This category refers to a concept of hypersensitivity or heightened reactivity to specific properties of stimuli in the visual environment. Stimuli are experienced as over-intense akin to the experience of sound as too loud.

Participant G describes as a younger child a particular hypersensitivity or difficulty with brightness of light or colour which was felt to be over-intense, painful to the eyes, unnerving:

G: I think, umm, like I said things that are very bright, a room that was all orange and yellow or people were wearing bright clothes when I was younger gave me the same visual thing as music that was too loud, too much of a shock as it were to my senses. I don't have that now but I'm just not bothered about things.

... It just hurt a bit, it hurt as if my eyes hurt.... It was to do with how bright it was, umm, not any colour in particular but something that could be bright, like an orange or a red, would seem sharp as it was very clear and it hurt.

Participant G states a clear preference for an absence of bright colour:

G: .... but as I say colour doesn't interest me. I'm happy if the thing could be black and white and grey, I'm happy if everything could be the same so it can be unnerving to have something that's very colourful but I certainly don't enjoy colour or anything visual at all I don't think.

Participant G description of his dislike of lines on paper and flashing bright light also suggests a degree of hypersensitivity to sharp contrast within the visual field which produces a similarly aversive impact:

G: It hurts to look at them [straight lines] on a piece of paper. It sort of feels strange because a straight line is usually either black on white or it stands out for some reason or something that's got an edge that's either sharp, visually sharp to look at, to do with I suppose the intensity at which you have to look at it and focus - that hurts in much the same way as something that hearing hurts, slightly behind my eyes I think.... I just want to turn away, it seems to hurt in the same internal sense that certain sounds do but I just don't want to look at them 'cos they look very sharp and they look...

Participant G suggests an internal echoing or perseverative effect reminiscent of that described in relation to sound which contributes to the unpleasant impact of unexpected or repetitive flashing lights:

G: Obviously a flash or something going off like a camera, like a light being turned on, something that's on and then off, like something that's flashing or something that's flashing is repetitive is just the same as a sound in that it's there after it's gone in my mind so it's the shock, like my ears aren't expecting to hear something like my eyes aren't expecting to see something, in it's brightness. I've never liked things that most people think would be ordinary but I'd think them too bright.

Participant G's hypersensitivity to brightness is described as having been a generalised phenomenon in childhood in that it tended not to vary from one situation to the next.

G: I think when I was younger I always didn't like things that were particularly bright. I think bright as opposed to shiny, I think I was quite happy with things that were shiny, paper and objects, but a colour or a room was to do with how light it was. If it was well lit and it was very reflective, like that, so that I could see it. I think the brightness of the colour I didn't like.

Participant G identifies a number of direct and indirect consequences arising from this hypersensitivity. As a younger child he recalls avoiding certain situations:

G: At first I mean I would stay away from places that were very brightly lit, I suppose especially going somewhere at night where they've got a lot of lights on. Not so much sort of sun in the day but going somewhere where there is unnatural light. I didn't like that too much.

His dislike of straight lines is identified as having led to problems with certain aspects of school work:



G: Umm, gradually I've got away from doing the kind of work that it involves but I mean things that do involve lines, sort of graphical work, I've always had severe problems with.

More significantly Participant G describes a developing recognition that his experience with brightness and colour was not shared by others and as a factor which contributed to his 'differentness' from others:

G: I think overall it's probably a very minor problem compared to sort of other things the way it could be to other people, it's a sort of slight nuisance not liking the brightness of things. Umm I think my lack of interest in the sort of visual side of things is probably quite a major problem in getting on with other people.

I mean I know not everybody enjoys art and things but my liking for things to be very black and white, in preference of radio to television, or books to pictures, certainly when I was younger, when a lot of children are interested in visual things more than others. I think that just caused a slight problem and I'm sort of still not interested in something that's advertising if it's very bright. So it took me a long time to realise that other people didn't think this (right) and I always thought that a world that was black and white and grey would be much better (right). But I quickly learnt not to say that 'cos it wouldn't seem appropriate.

While this hyper-sensitivity is primarily described in the past tense and within a childhood context some continuing difficulties remain. Participant G describes an ongoing difficulty in adapting to sudden changes in brightness and a management strategy to minimise its aversive impact:

G: Yes, I never liked bright lights. I'm always slightly happier in a room that's sort of slightly more dimly lit. I don't like seeing when a light goes on and it suddenly goes bright, that sort of thing.... Well, now I always have to, when I put a light on when I go into a room, I shut my eyes. When I go into a room I shut my eyes first and see it through my eyelids (right) because it's too much of a shock to just go



and turn the light on because of the nearness to it, it's too bright I think.

This experience of hypersensitivity to certain properties of the visual environment or hyper-intensity is not described by other participants.

### **Specific aptitudes and deficits**

#### *Judging distance, size, depth*

This category refers to participants references to and descriptions of their visual perceptual skills in judging distance and/or size or depth/height.

Two participants describe difficulties in judging size and distance.

Participant D describes problems leading to the misjudging of the size of objects viewed from a distance. He describes a tendency to judge size in a literal way in keeping with what he actually sees and therefore to judging distant objects to be smaller than they are:

D: Usually smaller. Like I went to a power station, I mean we were in the control room about 200 yards from the coolant towers and I thought they weren't very big. There was a sort of a bottom bit, a gap at the bottom, I thought that I was about as high as the gap and it turned out the gap was about 30 or 40 feet high.

D: It looked about a couple of hundred yards away but it was probably further.

D: Well yea, I've not only seen that thing with the coolant towers, the Humber bridge was another one. When I looked at that it didn't seem very big but when you actually got on it, it was huge, the big... have you seen the Humber bridge?

... It's got these huge supports for the wires. I didn't think they looked very big but they were.... And another one's power cables. (Right) 'Cos you know those cross pieces, I thought they were about that big

(indicating very small). ... but it seems to happen quite a bit, misjudging size.

Participant G describes a lack of reliability in his perception of size which can lead to misjudgments;

G: Yes, I've got a real problem with perception and judgment of how things are when they're far away and even when I get close. I think that's to do with what part of the brain it is that has sort of sight and perception in, and judgment, (right) how tall someone is, I've no idea when, you know, when they're far, when they're walking towards me, perception of how high a hill is or how big a tree is. ... when someone was walking towards me and at first I thought it was a small boy, then I thought it was a man, and then a small boy again, and when he walked close I saw it was a man. It was the height thing, I was trying to judge it against other things and I couldn't find anything to work out how tall this person was until I could see them close.

Participant D's difficulties with the judgment of size are however, described as confined to distant objects whereas for Participant G the problems are more widespread and include judgment of depth and height and problems with motor coordination. Consequently walking and moving around are described as requiring active concentration:

G: Misjudging things was a big problem as a child, umm, for movement around and jumping, whatever, misjudging distances between things, banging into things, falling over, you know, stepping down steps and things, made me seem very clumsy (right) and I mean I still am to a certain extent, when I try and put something on a table, if I miss it or I drop it, that sort of thing, I can seem quite clumsy, missing things when I pick them up.

G: Oh yes, if I don't concentrate on it, [stepping of kerbs] I mean I will fall over when I'm walking around, I have to concentrate on where I'm

putting my feet because if I do it without thinking, I'm likely to sort of trip up, that sort of thing (right). I think that's just a perception difficulty. ... I mean, I don't like stairs but I don't like lifts even more so I do stairs

In addition Participant G describes a fear of heights which has persisted since childhood:

G: I've never liked heights so I don't like looking at something that is high up or being high up, that sort of thing. With heights, if I'm on the ground and I look up beyond a certain height, it all looks a bit sort of blurry and a bit swimming because it's so high up to me, sort of relatively, I don't like that and it's just the same looking down but I don't want to be high up. ... Not being able to see it clearly, and sort of feeling unsafe, vertigo, that sort of thing....

However, the dislike of heights has been contained and has not led to phobic avoidance:

G: ... but I've always been slightly uncomfortable with heights, not completely afraid and not able to do it but just a feeling of being unsure and not liking it.

As a younger child Participant G recalls that he would try to refuse to participate in activities requiring him to face his fear. However, as he got older the need to fit in socially and not make a fuss in public and his parents firmness meant that he tolerated situations in which he remained uncomfortable:

G: I think perhaps when I was younger, if I could get away with refusing, I would try and refuse to go somewhere but my parents were usually quite firm which I think was quite sensible which means so that eventually I would, I mean wouldn't want to make a fuss in a public place so I tended to do what I was told a lot but I was certainly very uncomfortable.

Participant G describes himself as a cautious person, careful to limit or avoid sources of danger to himself or situations out of his control:

G: I think it's 'cos I'm very keen on limiting all sources of danger to myself just sort of naturally, it's the way I am - quite careful, and so in something that's like a lift or high I am obviously more worried about things causing problems, being out of control.

When anxious awareness of danger of falling is heightened:

G: Well, yes, that's right, I feel sort of up tight and tense, a bit more worried, a bit more sort of, I suppose in a sense the height, I'm more aware of the dangers of falling, that sort of thing.

Participant C described a problem with escalators which may be related to a difficulty with judging depth or height. However, C was unable to articulate exactly what it was that he found difficult. However, when asked to reflect on his biggest sensory-perceptual difficulty he rated this problem with escalators as possibly his biggest:

C: I didn't particularly like going down the really big escalators on the London Underground. ... I didn't particularly like the height of those London underground ones. After I got here there's a department store in the city called John Lewis and I got trapped on a Saturday morning at the top of an escalator with a long queue of people behind me. ... I was all right going up escalators, just going down them.

Participant G suggests that 'seeing in two dimensional' affects his perception of pictures and photographs and contributes to a lack of interest in them:

G: I certainly don't like pictures because of their not being real so that they don't look like much to me - photographs, that sort of two-dimensional...

In contrast Participant F describes himself as being particularly skilled in detecting embedded figures: Participant's B and F regard spatial judgment and the judgment of perspective as unproblematic and even areas of particular aptitude or strength:

F: Yea, I think I sort of still am really, I sort of see things maybe ummm.. ah, yes, I can find shapes in things, like mum had this book and it was, had a square and you had to find a shape in there (yea, yea) and I did it sort of first time and mum and dad had been taking half an hour over it and I saw that straight away  
(Right) Most things like that really. (Uhum) Pattern in a pattern I can see, I don't know really.

B: Yea, I'd say I'm kind of like, my judgment is obviously, my judgment of distance is more accurate (right) definitely, umm, my judgment of size, my judgment of everything is more developed (right). I think I've got quite good coordination because I juggle and I learned Unicycle and all of that (yes). I think my spatial awareness has always been good. ...I think my visual awareness has always been fairly good, in fact it's my peak skill!

F: I think perspective has always been, I like perspective! especially in drawing, I have to sort of have to get it right otherwise it doesn't sort of work and I get really upset (uhum) but. ... Mum says I'm very, I can climb up mountains and that sort of stuff and always know where to put my feet (uhum) sure-footed I think she says I am.

## *Touch*

### **People touch**

This category relates to participant descriptions of their experience of different forms of social or 'people' touch: physical contact and interaction with people as distinct from objects. Subjectively the researcher found discussion with participants around this issue the most sensitive part of the interview. In particular the researcher's experience was that some participants found this a difficult area to talk about. Given the intimate connection between this aspect of sensory-perceptual experience and the whole area of sexuality, and the age of many of the participants this is perhaps unsurprising. However, there was also the sense that for participants this aspect of relating to people (and social impairment is currently considered the core of autistic difficulty) was one which highlighted their 'differentness' and was therefore particularly sensitive to discuss. The following is an extract from a reflective log written immediately following the interview with Participant B which summarises the researcher's thoughts on that part of the interview dealing with this aspect of the participants tactile experiences:

I had a strong sense that questions about hugging and affectionate contact were difficult for B. In response to a question about change in experience of touch as an adult B looked uncomfortable and his answers were not elaborated. When asked at the end of the interview for feedback on the interview process itself, B identified the area of touch as one that other interviewees might find difficult. I myself felt that I might have handled this part of the interview more successfully.

There was variation between participants in the extent to which people touch was considered a significant or problematic issue in their lives. Participants B, F and G identified aspects of social touch as a difficulty in their lives, past and present. Participant E identified problems in tolerating only one aspect of

social touch, that of 'tickling'. Participants D and C on the other hand *did* not report people touch as problematic or as a particularly significant aspect of their sensory-perceptual experience. However, answers to questions around this aspect of touch elicited in these two interviews minimal levels of descriptive response and in Participant D's case there was a strong suggestion that social touch was tolerated rather than a sense of comfort or enjoyment of physical interaction with others.

*People touch: part of a wider difficulty with people*

Participant G describes as a child a generalized difficulty with physical contact with people with whom he suggests he is much less confident in his interactions than in his interactions with objects:

G: Yes, it felt wrong - I suppose people felt different from objects, feeling sort of warm and stuff, I didn't like them. ... Umm, in a way objects are easier because people were too complicated, I mean I've always had a problem with how hard you can touch things. I mean when I used to play with my brother and sister I'd perhaps hurt them very often without intending to because it was hard for me to make the distinction from playing with people of my own age, if you sort of play rough and tumble, if you do that with a baby that's very young, they're going to be hurt quite easily and I mean, it's just that, the difference of you know not wanting to damage something that could be quite weak, I could understand an object slightly more. I never liked delicate things, I liked things that were quite - like building blocks, quite rugged, I could chew them or drop them and they'd be all right, rather than hold.. I'm always uncomfortable holding something that if I drop it might break.

These problems with social touch are described within a wider context of difficulties in understanding and trusting people:



G: Ummm, I suppose it's because of two things, that in a way it's not just touch, in a way it was being uncomfortable with other people, with a sense of unknown, not knowing, not trusting. I mean it used to be better with children because there was a time when I trusted everyone completely but sort of through experience I then learned not to and they it was sort of no different.

### *Affectionate touch*

Participant G describes affectionate touch as particularly problematic and evoking very strong escape or avoidance responses:

G: but I think more of a problem is that I'm not very, I don't like physical touch, that sort of thing, shows/ displays of affection, that sort of thing, you know. Umm, so I don't like that, umm...

G: It feels very uncomfortable to be that [held], because it feels unnatural and doesn't feel at all sort of pleasurable, that sort of thing... Oh yes, yes, it's something that I want to break away from instantly without really knowing why, it just feels very uncomfortable and it's not something I want to do.

Participants B and F also describe significant problems in dealing with affectionate touch such as being hugged or held.

B: Yea, I didn't used to like it [being hugged]. It was umm, I preferred to be independent I suppose, or to have autonomy of some kind.

B: ... grown-ups were kind of, grown-ups were big I suppose in comparison. I thought, I used to think they were big and well, smelly I suppose, and a bit sweaty, and I was worried about germs...

Participant B clearly identifies the emotional content of touch as the core problem for him, differentiating it from other forms of physical contact with people which did not pose a problem for him:



B: Ummm... a minor or a major - oh, anything that was a problem around touch? (Yes) Ummm, it was just, umm, I suppose, if it was accidental touch then it didn't used to bother me. If it was just for the umm, if it was towards some purpose like helping someone up hill or something like that, that didn't bother me either. If it was touch just for the sake of touching and nothing else, if it had some emotional content to it, then I couldn't handle it, really (right, right), it was just umm, I was defensive, when it was someone else's emotions I just used to try and fight them off, someone else's emotions kind of made me feel like I was, something was going to happen that I wouldn't be able to deal with, I used to want to hide from it I suppose.... I just used to hide from things I couldn't understand and the emotion in other people fitted quite well into that category.

Although not specifying emotion, Participant G also suggests that a lack of understanding underlies his strong aversion to gentle touch or stroking:

G: No, I mean, I keep saying uncomfortable, unnatural, it's that sort of thing - not wanting it at all, it doesn't hurt, it's just something I want to get away from because I don't like, perhaps 'cos I don't understand it but I don't like it.

Later he suggests also that confusion over his own emotional response as well as that of the other is also problematic for him:

G: that's perhaps a good expression [Temple Grandin quote] of why I don't like people touching me, the sort of pleasurable, sort of emotional sensation (right) perhaps being a bit confused over what I should be feeling.

Being in control of the interaction is identified by Participant F as critical in mediating the impact of affectionate contact:

F: Nnno, if I wanted it, then I'd be all right, but if I didn't want it, then I really didn't like hugging - I still don't - I don't know really. ... I feel like I'm being squashed, especially when my dad does it.... Yea, and constricted and sort of not being able to move, and having no control over the situation.. (uhum).... Not upsetting really, just sort of annoying really. ...Yea, if I'm hugging someone, that's all right, if they're hugging me, it's not right.

Participant B also describes the acceptability of touching others on his terms, although it is clear that this touching was in childhood not a display of affection, and indeed took place without a real understanding of the personhood of others:

B: Yea, very different I should think, very different..... I don't know, I don't know, it's just - sometimes I used to have a slightly strange urge I suppose, strange urge to go up to someone and umm and take their wrist or something like that (right)... and of course because I wasn't aware of the other person as, not really aware of them as a person as such, then umm I didn't feel as if I was invading anyone else either (right, right). That thought didn't really occur to me!! (Yes!)

Participant F suggests that affectionate contact with younger children is less problematic than with older adolescent peers or adults:

F: Well, little children it's all right yeah

Participant G indicates an awareness of the impact on his family of his difficulty in tolerating physical affection:

G: Well yes, I didn't like, I've never liked other people sort of touching me and that obviously makes it harder even as members of the family to sort of want things, at times, very brief times, I can sort of cope with it but I always seem a bit stiff, my parents said I was sort of very unresponsive as a young child and sort of didn't like that sort of thing.

*Playful touch*

A number of participants, Participants B, F, E and G indicate a current or childhood dislike of playful tickling. Participant D's description suggests that tickling was tolerated rather than enjoyed while only Participant C recalls enjoying the experience.

D: I can bear it [being tickled], yea.

\*R: Do you enjoy it?

D: Not particularly.... Uhum [tolerate it]

C: I used to like, I used to end up, sometimes I ended up giggling.

While tickling was not perceived as unpleasant in childhood, Participant G nevertheless suggests that his reaction to it seemed different to other children and it is something which he no longer enjoys:

G: Yes, I think so [liked it as a child] but I think it was different from when I see other people being tickled, they sort of laugh, what I would do would be to squirm away from it, get away from it, but then want to go back again. (Right) I don't like it any more, I used to like it as a young child.

Participants B and E suggest that underlying the unpleasant impact of tickling was a feeling of loss of control

B: If I thought I was about to be tickled, I would be very defensive, it's something, I would do anything to avoid it. It's not as if I was afraid of it in any way, I was just quite defensive about it because I felt, I think it used to make me feel invaded (right) and when it actually happened umm I suppose I, it was as if some other force was taking control of me and I'd gone into defence mode and there was nothing I could do

about it, I was just constantly (right), it was like umm, I didn't like it because it used to make me lose control.

\*R: Can you remember what it was about that [tickling] that you disliked?

E: Just being out of control.

Participant F on the other hand describes a very definite ability to control receptivity to tickling which is under his control

F: Apart from on my feet, I'm not ticklish at all (oh I see). Well, I can be ticklish if I want to be like when someone at school tickles me, especially this girl!! (Yes) I can be ticklish or cannot be ticklish, ummm.. mostly I can stop myself from being ticklish (right). It sort of puts her out a bit..

#### Other social touch

A number of participants also describe difficulties with other forms of physical contact such as accidental touch or other social touch. Participants F and G unlike the other participants, report finding casual physical contact such as brushing up against another in a social setting unpleasant:

G: I don't like crowds anyway but the sensation of touching someone I just don't like at all.... Obviously it's a real problem, I mean I learned to control it, a sort of repressed sort of shudder - it's more of a problem if I'm anxious you know in that I mean that I can just get fed up and go away and want to get out of it completely.

F: I mean people in shops and I accidentally bump into them or people bump into me it's very, I don't like that really. ... it makes me feel like it's my fault or something... I don't know really. I think it's the sense that I actually didn't want to do that.

As with Participant G earlier, Participant B also reports a childhood dislike of social contact such as shaking hands but suggests that this was due to a cognitively based fear of germs:

B: and also shaking hands with people... I suppose I used to think it was slightly unhygienic.... I used to be very worried about germs.

However, participants did not indicate that other forms of playful physical contact such as rough and tumble play were problematic for them:

B: I suppose it depended on the other children! (Right) I don't know, I don't - actually I don't think that was a problem. I used to, I used to join in kind of wrestling games in the playground (right) and I didn't mind that.

Developmental changes and other factors were identified by participants as impacting on aspects of their experience of people touch.

While there is a recurring theme of continuing difficulties in this area there is also (with some exceptions in particular areas), a strong sense that these difficulties are gradually ameliorating.

G: Obviously with people I don't know, I'm not very good with people I don't know, I used to not want to talk to people at all but I mean.. I mean like everything I suppose I'm gradually overcoming it, it's not a problem to shake hands with people, that's sort of natural.

Participants F and G describe an increasing tolerance of physical affection at least in some situations or for very brief periods:

F: No, it's not as bad, but it's still pretty bad...!

G: There have been times when I'm able to get close to my parents and it's OK but even then I could perhaps be comfortable to be touched by them but not for very long (OK) that sort of thing.... I'm not sure, it's

sort of, I can't think of anything to connect it all but sometimes I'm sitting doing something, I'm happy for my parents to be you know holding me, but sometimes I'm not, I want to be distant from them.

Participant B confirmed that his experience of physical affection had changed but perhaps understandably appeared reluctant to go into detail about this. However, his difficulties with affectionate contact are described in the past tense:

B: Yea, I didn't used to like it [being hugged]. It was umm, I preferred to be independent I suppose, or to have autonomy of some kind.

The role of social learning and social experience can work both ways; to gradually increase tolerance of people touch or to decrease this tolerance. Trust in other children and therefore physical contact with them changed for Participant G because of negative social experience:

G: I mean it used to be better with children because there was a time when I trusted everyone [children] completely but sort of through experience I then learned not to and they it was sort of no different.

Participant E on the other hand describes induction into peer mores as an older child leading to a change in his attitude towards physically affectionate gesture:

E: I, I, err, I found it all right but as a I got bigger, of course I thought it was sappy the way other kids do...

In addition mood state is identified by Participant G as affecting tolerance of incidental physical contact with others:

G: I don't like crowds anyway but the sensation of touching someone I just don't like at all. ... Obviously it's a real problem I mean I learned to control it, a sort of repressed sort of shudder - it's more of a problem if

I'm anxious you know in that I mean that I can just get fed up and go away and want to get out of it completely.

### **Tactile hyper-sensitivity**

This category relates to participants descriptions of their experiences of aspects of non-social touch i.e. tactile reactions to materials, objects and other non-social events. It includes tactile sensations which are subjectively perceived by participants as problematic or unpleasant and experiences of perceived accentuated or hyper-sensitivity.

All participants described some form of problematic sensitivity to non-social tactile sensation. All described a dislike of skin contact with at least one fabric or material and in addition a number of individually idiosyncratic sensitivities were described.

#### *Fabrics and materials*

A number of participants disliked wearing or having contact with wool against the skin.

F: No, I hate wool (right). Umm, any really big heavy things that itch and are awful and have great big lumps in, I don't like that. ... Oh yes, I hate that, yea....[It feels]I think constricting or something ummm..... it's very odd.

D: Yea, I think it's just the wool was itchy.

C: I didn't like anything that was knitted (right) or woolen because I would not wear thick pullovers.... I can't remember. It could have been the feel of wearing something woolen.

G: I didn't like having a woolen jumper with a short-sleeved shirt so that I'd have the feeling of wool against my skin. Now it's not a problem but I remember that when I was younger having a real problem with that, if I wore a jumper that was mainly wool or something that felt like wool, I'd have to wear a long shirt under it so that it wouldn't be touching my skin.... It was itchy and it sort of rubbed a bit, it felt a bit rough.



In addition to wool, the feel of new clothes and particular types of clothing were also described as unpleasant by a number of participants. Participants D and E recall a dislike of wearing new clothes:

D: New clothes tend to sort of like itch a bit (right) but..... Oh yea, I don't really like wearing new clothes until they've been washed a couple of times 'cos they sort of itch. I don't know why. I don't really know, yea it's the itch. I don't know whether it's some chemical they put into it.

E: [Bothered] Only when, only that they [clothes] were still a bit stiff from being new and that tended to wear off.

Participant E also described a strong dislike of fitting on and wearing new shoes which generalised by association to a strong dislike of shoe shops themselves:

E: But I've always had problems with shoe shops. I remember when I was a kid, I couldn't stand shoe shops. ... It was always hell going to shoe shops and, a lot of its the fact that it's not always easy to get shoes that fit my kind of feet (right)... and so when I was a kid I was, when I think of it now, I was always trying to squeeze my shoes, squeeze my feet into shoes that were too small. ... Yes, and... a lot of the time the shoes were stiff cos they were new (right) so they had to learn how to give... Well I just didn't like it, it was very unpleasant. Well that was the main thing, the fact of trying on shoes (OK) and they were never going to be fully comfortable right away.

Participants B and E found wearing particular types of clothes uncomfortable:

B: Yea, I didn't like to wear jeans because they're kind of, jeans are kind of, I used to wear tracksuits 'cos they're light and they umm, they move around easily, whereas jeans are stiff and they crease and all that kind of thing.... I think for me it was just to do with things like jeans, that kind of material used to crease and bend and kind of it used to



rub.... Just uncomfortable.... I preferred tracksuits for a long period of my life.

E: I remember some clothes were more comfortable than others.  
... Well [I preferred] the ones that didn't cling too much (right) and, I still don't like wearing a tie. I don't do that unless I have to. It's curtailng.....

Participant E also described a strong dislike of the feel of wet clothes against his skin:

E: .... if I was wearing socks and they got wet I didn't like the feel of that.

E: and when I got, if I got water all over me and all my clothes were wet, soaking wet, that used to bother me as well.... The way it was clinging to me and it was all clammy.

This is described in one incident as leading to his tolerating another very unpleasant situation rather than face the prospect of moving in wet clothes:

E: I remember a time when we went out in the boat across the River Dee and I think it might have been the Dee, it might have been the Orwell (right) but I remember I was in the bow of the boat and there was this wind and waves and the water kept splashing down my back and, I must have been about seven, but I was upset about it.... I was lying in the bow of the boat and my sailing jacket was forming a funnel for the water to go down (right) and I knew I didn't like it but I just couldn't bring myself to move away from it because I didn't like moving in wet clothes. ... Yes, all the water and the wetness and the fact that it was clinging to me and feeling uncomfortable.

Participant G described a sensitivity to touching very soft materials or fabrics:

G: Yes, I've never, I always, partly perhaps 'cos of the way it looks but always touching things like that that are like cotton wool or the foam in mattresses, that sort of thing, that feel very soft to touch, that give a lot to the touch, they make me feel very uncomfortable, the sensation of having it next to my fingers always makes me feel very uncomfortable and makes me shiver a bit and not want to touch it. (OK) I'm not sure why but (you would actually try and avoid it?) certainly I would try and avoid touching anything like that.... I've never liked, I always hate cotton wool and things that feel soft, that I can't get a firm grip of in that sense,

G: Ummm, something that can be like velvet is unpleasant, it's not quite like cotton wool but it's something where like if you brush it one way it's OK but brushing it the other way feels wrong. That, it feels very prickly and I don't like that. So it comes under the heading of quite soft things really, it's a slightly different sense to cotton wool but then most things are just non- feeling at all.

However, in addition to tactile hypersensitivity a number of accounts suggest that other considerations may also have played a role in aversions to specific types of tactile sensation. With regard to new clothes, Participant B suggests that the unfamiliarity of new clothes was a key problem for him:

B: I suppose it's just to do with the fact that they're a different colour, a different, slightly different shape, they've got a different pattern on them. I mean they're something new and unfamiliar and I suppose it took me a bit of getting used to before I felt like it was part of me.

Participant B also explicitly suggests that he was and to some extent still is unable to ignore situations and irritations which other 'normal' people are able to dismiss and move on from without difficulty:

B:... but I think there were many things which used to irritate me and I used to have to talk about which other people if it happened to them would just ignore and carry on their everyday lives. (Right) And I think it still is that way to an extent. Certain problems I come across I have to talk about where other people would just ignore them and carry on as normal.

In addition Participant B suggests that the effortfulness in putting on and taking off items such as jeans may also have contributed to his preference to avoid wearing them:

B: ... In fact I think it was the sensation of having to put jeans on, I found it difficult, awkward, to umm, and they'd brush against me too much.... And it was umm, it felt like a lot of effort to have to go to put them on.

Similarly he describes a preference for going barefoot which is not based on any difficulty with wearing shoes and socks per se but more to do with avoiding the effortfulness of putting them on:

B: Probably, [enjoyment of going barefoot] because it was easier than having to put on shoes and socks. ... I suppose it was just the act of having to put them on.

Participant F suggests that a dislike of change rather than a difficulty with texture or tactile sensation per se contributes to an aversive response in certain situations. This negative reaction and experience is ameliorated by a process of familiarisation:

F: Yes. Yea, yea, I mean, I could be moving, this time next year we could be living somewhere else and I, things change and I don't like it, I think change - when I had my carpet changed in there, I liked it because it's really long, well not that long about this long (uhum) and I liked sort of standing in that and sort of sinking into it but now it's sort of really short, it's like this one.... It wasn't so much the change in

texture, it was just the change, sort of one time it being really long and another time it being really short and feeling different. (Uhum) It wasn't so much I disliked or liked the different textures it was just sort of the change.

F: Yea. I can get, it's all right once I get used to anything really.

*Body-based and self-care sensitivities*

A number of participants report being particularly aware of and sensitive to tactile sensation related to use of hands and fingers and report an unpleasant experience of some grooming activities.

A number of participants recalled a dislike of dirty or grubby hands and fingers:

D: Well greasy (right). I mean if I haven't washed my hair and sort of run my hand through my hair I get a bit greasy (right) I'm very conscious of that, I have to really wash it clean. (Right) I hate having greasy hands, when I've eaten chips or something with my fingers.... [Wash hands] whenever I've like touched anything greasy. Like if I haven't washed my hair or I've like been eating chips with my fingers (right) - or even with a knife and fork sometimes.

F: I could go and dig in the garden for ages but I'd have to come and wash my hands to get rid of the feel of the thing. I'd still have the marks, the dirt on my hands but if the feeling of the soil's gone, I've got used to it, then that's all right.

Participant B describes a more pragmatic reason for his dislike of dirty or sticky fingers which nevertheless suggests a finely tuned awareness of sensation in his fingers:

B: Partly to do with hygiene (right) and also if I'd got, if it was sticky between my fingers I used to find it inconvenient. I think I still do.... 'Cos it means whatever you're doing, decide to do, you might get it on

whatever you're doing and also it's slightly harder to move your fingers.

Participant G on the other hand suggests a tendency towards reduced sensitivity in his hands and describes his awareness of the condition of his hands as a more recent phenomenon which is not yet reliable:

G: Umm, for a long time I didn't notice and the only reason my parents knew my hands were sticky is 'cos door handles would feel sticky and I wouldn't have been aware. I think perhaps more recently I've not wanted them to be sort of dirty or sticky.... I mean, there again over dirtiness at times I've had almost a fetish of making myself wash my hands again and again and again, and yet at other times like the drinking if I just get out of the habit, you know I could've got my finger nails caked with dirt and be quite grimy and I might wash them say once a week or something (right). It causes problems because it's just like, when I get out of the habit, if I don't make something a habit, I don't remember to do it. I have to remind myself to do it.

A number of participants described sensitivities or fears around basic self-care and grooming activities such as having nails cut, or hair cut or washed. Participants G, B and E all reported an unpleasant experience of having their nails cut but their descriptions suggest different causal explanations for this.

Participant G suggests that he found a changed or heightened sensitivity around the finger-tips underpinned his dislike of having his nails cut:

G: I don't like having my nails and toe nails cut. It feels strange. I suppose it's 'cos sensation's like focused isn't it on the touching on the very fingertips and things or something - but it always feels very strange, in fact when I touch my fingernails after having had them cut, they feel very uncomfortable.... it's OK while they're being cut, after they've been cut, when I touch something, then it feels different, they feel sort of short and stubbly. I doesn't hurt but I feel I've lost some of

the sensation I had before, or it's just difference, I don't like it, and it's knowing this is going to happen that I don't like them being cut.

G: ... I avoided it more [as a child], I mean now I can cope, I perhaps feel the same but as a child I couldn't put up with it.

Participant E on the other hand suggests that his dislike of the procedure was based on fear of injury and lack of control:

E: I didn't like it,[nails cut] it was a chore I liked to have over with. And it's something I liked to have done as little as possible. Yes, I was a bit frightened of the big blades coming so close to me and under the control of somebody else.

Participant B was less able to articulate the basis to his dislike:

B: Yea, I can remember not liking my nails cut I suppose.... I think it was just awkward.... It's difficult to remember.....Yea, I think it was just the sensations associated with some kind of an awkward feeling.

Participants E, C and G reported a strong dislike of having their hair cut but again offered different levels of explanation for this. Participant E explains that an intense dislike of the itchy sensation of little bits of hair on his neck led to screaming and avoidance:

E: Well only because the hair went down, went down the back of my neck and started itching.... Well it was just itchy and irritating.

E: Yes, all the time. [screamed, avoided]

Participant C was unable to recall what it was about the activity which upset him but indicates that his reluctance to have his hair cut as a young child led to special arrangements whereby a hairdresser visited him at home:

C: Errr, oh, I didn't, oh, I wasn't all that keen on it (aha) at first but I got used to the fact that it grows (yes) and you cut it occasionally. ... I can't

really remember.[what it was that he disliked about haircut]... the hairdresser I used to visit used to come round here when I was much younger

Participant G on the other hand indicates that his difficulties were socially based and to do with interaction with other people outside of his family rather than any difficulty with the actual hair-cutting itself:

G: Yea, I didn't like having my hair cut. I didn't have it cut at all at first. I didn't like having to have a hair cut because it meant going to a barber's shop or a hairdresser's and having strangers touch me. I was quite happy for my parents to cut my hair but obviously that was a problem because they weren't professional hairdressers and what they would do would not make it look very good and that would sort of make people single me out and would draw attention so I went through a long period of only having it sort of just trimmed at the ends by my parents, they just cut it off slightly, but the school I've gone to has a policy of having hair you know above the collar, that's a school rule, and it has a real problem. It's partly I felt a slight sense of loss, a part of me losing my hair as it was, but I think more the problem wasn't having my hair touched, it was having someone strange because I make a lot of mistakes 'cos going to a hairdressers you have to indulge in conversation which I found difficult, I found it very difficult to talk to someone I didn't know or hadn't prepared for, that sort of thing.

G: No..not really, no, I mean I've always been slightly afraid of sharp objects but I was quite happy to have my hair cut, it wasn't the sensation, it was the people who'd have to do it.

Participant B describes a particular hyper-sensitivity around his ears:

B: Actually I didn't used to like, I didn't like, I didn't used to like sticky things, especially when they went near my ears. (Right.) I used to hate the thought of getting cake or crumbs around my ears... Getting well,



cake or honey or anything that was slightly sticky, when I'd just been eating it and it was all over my fingers I didn't used to want to put my fingers anywhere near my ears...

... I just didn't like the thought of getting anything sticky around them - also, if something was to, if something was to hit my ears suddenly or something was to tug at them, I'd be, umm, they'd suddenly go hot and I didn't like having hot ears.

... It's to do, I think it's something to do with the way the nerves are within the ears and the ear lobes. You know if something umm, something tugs at your ear lobe the blood supply increases and it goes hot.... Yea, heat and stickiness round the ears I didn't used to like.

This sensitivity is described as interfering with Participant B's ability to concentrate on other activities and as leading to some unusual 'compulsive' behaviour:

B: Yea, and it used to really annoy me. It used to really bug me when that happened (right) so I used to keep putting water on them all the time to try and cool them down but it didn't seem to work.... but umm, it was as if unless I could get my ears clean and cooled down again then I wouldn't be able to do anything else, or concentrate on anything else.

These accounts which are described primarily in the past tense suggest that problematic reactions to non-social touch and tactile sensitivities were experienced as a greater problem in childhood.

E: They [problems with touch] used to be a big problem for me when I was a kid.... I usually used to complain and say I didn't want it.

### **Food Dislikes**

Several participants describe a dislike of certain food primarily on the grounds of texture. Participant B suggests that a dislike of cooked vegetables arose in part at least from a solid appearance which belies a soft texture:



B: ... When it[carrots] was cooked it was all kind of, at first it was solid and assuming you put it in your mouth it goes mushy.

Participant G also describes a dislike of cooked vegetables:

G: Err, I'm not allergic to any foods but for taste I tend not to like very steamed vegetables that taste soggy as it were and I don't like having to eat those but there's nothing I absolutely can't eat.

Participant E suggests a strong preference for food which had a very definite consistency, either fully liquid or fully solid:

E: Yes. I used to hate things like, which were all soft and gruely like Readybrek and Farex (right) and I couldn't stand that and when I saw my sisters eating it used to make me feel urrgh!... Yes, I used to like having things that were either fully liquid like soup or things that were properly solid, that you can get your teeth into. I've never liked anything that was all gruely.

Participant F on the other hand suggests that breaking habit or unfamiliarity is the primary reason for his dislike of foods such as vegetables. However, a wish to fit in socially is now proving an effective motivator in overcoming his reluctance to eat 'new' foods:

F: No, I think it's just because I've never had them[vegetables]. I can't get used to it really.

F: If I'd eaten vegetables when I was little I probably would be able to eat them now but as I've never eaten vegetables, well I eat, I have started to eat carrots and beans, I ate green beans for the first time at the Centre (oh, wow). I wasn't sort of not going to eat them because I was sort of in a very big social environment and didn't want to sort of embarrass myself by not eating vegetables.

## **Tactile Fascinations**

A number of participants described particular tactile fascinations or tactile based activities which they enjoyed in childhood. Participant descriptions suggest that these were associated with several different experiences: those that produced a sense of comfort or security, those associated with exploration and play and those which were associated primarily with a sense of purely aesthetic pleasure or enjoyment.

### **Comfort and Security**

Participants D, E and F recall childhood enjoyment of forms of deep pressure touch: the sensation of being covered, tightly wrapped up or lying under cushions. Participant D describes this an 'occasional' activity while Participant F recalls enjoying this activity as part of 'bathtime'

D: Yea, I seemed to enjoy that a little [tightly wrapping up, lying under cushions]. ... I don't know, it just felt more comfortable like that. Cushions and duvets, yea, quite a bit.

F: After having a bath I like wrapping myself up in a towel and sort of crawling along the floor but... I don't know, I think it was a feeling of being encased, of me in control of how I am sort of encased...

Participant E recalls a sense of safety from being covered up by blankets as a child:

E: Yes. I remember I always used to pull the blankets up over my head when I was a kid and just felt safer that way. ... just being covered up.

Participant F suggests that part of his enjoyment of being underwater has to do with this feeling of being encased in a way which is under his control:

F: Yea, but only if I can get out of it. It's really err, I'm quite proud of myself because I've been wanting to do it but under water it feels like I'm encased (right), but I can get out of it...

Participants E and G recall the comforting experience of smooth satin-like labels or ribbons:

G: I mean as a child there was a sort of comforter thing, like labels on clothes, I used to like rustling them together, perhaps partly the sound but also for the feeling 'cos they were made of different material. I used to have that, I used to have one that I always used to drag round with me, I used to have that and it would make me feel a lot better, the touching of that.

E:..... I think maybe, I recall when I used to be a kid I always had a satin ribbon on my eiderdown (right) and I always used to do this with it (oh, right, rub it between your fingers like that) yes, and I always used to go to sleep rubbing it between my fingers like this. ... Yes, a kind of security blanket (right) and it used to help me get to sleep. I could never get to sleep without it.

#### Exploration and Play

Participants B and G suggest that the tactile quality of some preferred toys and materials was only part of the appeal which also had to do with other opportunities for play and exploration:

B: ... I suppose I used to like polystyrene.... It was good fun, and it was kind of warm to the touch and almost solid but not quite, and then eventually I could break it up into little pieces and make a mess... And I mean also I could pile polystyrene blocks up into very tall towers that touched, almost touched the ceiling.

G: I never liked delicate things, I liked things that were quite - like building blocks, quite rugged, I could chew them or drop them and

they'd be all right, rather than hold.. I'm always uncomfortable holding something that if I drop it might break.

#### Aesthetic enjoyment of touch

Participants B and F also describe childhood fascinations which would appear to have been primarily based on sheer enjoyment of the tactile sensation itself:

B: Yes, actually a nicely polished wooden surface, it's almost, frictionless I suppose I used to, I used to feel that out of fascination.

F: I liked smooth things... there wasn't anything very special about that.... anything sort of smooth really...

F: I think if it was shiny and slightly curved, I think maybe, or not straight, I'd don't really like straight things, if it was curved and shiny and metal (uhum), yea, I think I'd like that.... Yea, yea, marble, as well, I like great big marble things, I like touching..

F: Yea, I think, it was the surface my tongue had on that hard thing I think. I don't know why that was, it just sort of felt strange, I don't know why. ... I don't know, I think - oh yea - I think some kind of pencil sharpeners have that kind of raised lines, sort of rough (uhum) and I liked running my tongue along that, I don't know really...

In addition however, Participant F indicates that his tendency to touch objects within his environment happens without intent or awareness:

F: Yea, when I'm walking downstairs or walking along railings for example, I put my hand in railings when walking along and sort of going like that. Umm, walking downstairs running my hand along, what's it called, banister (uhum) - I don't know why I like that, I'm doing it for no apparent reason.... Yea, [do it quite a lot] doing it subconsciously I sort of just do it.

However, he has learned to inhibit this inclination in social situations:

F: Umm, I haven't, I think it would help to touch things, yea, but I don't really do it. I'm embarrassed by touching other people's furniture.

## **Smell**

### **Hyper-sensitivity to smell**

This category refers to very strong or intense reactions to one or more smells or odours. Two participants, E and C described their sense of smell as no more or less sensitive than others and did not report a strong dislike or heightened sensitivity to smell or odour. However, Participants F, B, D and G each report a strong dislike of at least one odour or smell and/or considered himself to have a heightened sensitivity to smell.

Participants described a strong or heightened reactivity to a number of specific odours, some idiosyncratic to the individual, others common to two or more participants.

Participants F, B and G all report a strong aversive reaction to the smell of perfume, deodorants or after-shave.

B: I used to umm, yea, I think I didn't used to like it when they smelt too strong because it was as if the person, as soon as the person walked into this room, suddenly you'd feel, you be overpowered with this massive great presence that had just entered your personal space when in actual fact it was only the effect of the aftershave so ummm (right), yea, I don't think I used to like it when people wore too much.

F: Some perfumes I don't like. Like some my mum uses, she puts, not loads but just enough on for me to smell it, and walks past and I sort of reel back in horror I think. It's sort of, some deodorant and aftershave I don't like either. ... [It feels] Quite intense, yea.

G: I think the biggest problem with smells is I don't like the sweet smells of perfume (right); when someone walks past me with perfume I have to breathe, have very difficulty breathing which obviously in company is a big problem. I mean I notice it walking down the street

or being in a room with people wearing all sorts of perfume I get overwhelmed and I can't cope with it.

Participant G also reports a strong dislike of another 'cloying' sweet smell, the smell of beer being brewed:

G: I really disliked, I've always disliked the smell of beer being brewed. There's a brewery down the road and when the wind blows I can't stand that 'cos it's a very sort of cloying smell, the hops being made and it feels as if it gets inside my nose and I don't like that.

In addition Participant F identifies the smell of cigarette smoke as strongly aversive:

F: I REALLY don't like smoke and I was sitting on a bus sitting inhaling cigarette smoke, and I really don't like that. [ I feel] choked really, errr, encased in smoke I think, but... Yea, I don't like it.

\*R: Do you think that's something to do with the actual smell or is it that you worry that it's harming you or..?

F: No, I think it's just the smell. ...[ I feel] Not panic precisely, I would just sort of sit there and take it but I would sort of internally feel quite panicky and sort of not like it. ... I'd sort of hold my breath and sort of run, run out of air.

Participant D reports a strong aversion to only one odour, that of the smell of eggs:

D: I've never liked the smell of eggs or anything.... Absolutely think it's totally revolting. It's got better recently (right) but when I was young I just couldn't stand it. ... I just hated it.... It was always that way, as long as I can remember.

The impact of these aversive reactions to specific smells varies from individual to individual. Participant B explains that while the experience is unpleasant it is not one which impacts directly on his behaviour:

B: I don't think it used to bother me as much as that...

Other participants however, describe a range of potential negative social consequences which may be influenced by a number of factors including the other people involved and the intensity of the aversive experience. These consequences include active avoidance of people or places associated with aversive smell:

F: If I liked the person, I'd sort of put up with it but umm if it was sort of very, very intense, I would have to sort of go away, brrr, move away or something, I don't know.

F: Prrrr, not really, I don't think, but yea, if I did know that they had something on that I didn't like to smell, I do avoid people who smoke. (Right). If I knew that, I would avoid them, yea.

G: It really bothers me, I want to get away from it.... Well, I mean it's a big problem socially isn't it, if someone walks past you and they're wearing a perfume and for me to go sort of "ppphh" (right) I mean obviously it's very unacceptable and I can find it overpowering if I'm having a conversation with someone who's wearing aftershave or something that I find too strong. ... It doesn't drown out them but that's what I'm focused on and because of that I feel uncomfortable and just want to get away I suppose.

G:... 'Cos I mean a lot of people would wear sort of strong perfume like aunts and relatives and for a long time I'd sort of associate not wanting to be with them, not on the merits of a person but not wanting to be near their house because it sort of smelt different I suppose.

Participant B describes his strong dislike of perfume in the past tense as a childhood phenomenon. Participant G and Participant F describe ongoing difficulties. Participant D indicates that as he has got older he has learned to manage his aversion to the smell of eggs better:



D: Yea, I wouldn't eat in the same room as people who were eating eggs. ... but I can sort of like ignore it now. ... Just ignore it, think about something else.

Participants F and G explain their reactions as experiencing these specific smells in a much more intense way than other people but not necessarily indicative of a general hyper-sensitivity to smell:

F: I think they[other people] did [detect the smell] but I don't think they smelt it like I did - strange. ... I don't think it's stronger, I think I just, it's more intense really, I just don't like it.

G: Sensitive in that I don't like something that smells sweet in that way. ...Those sorts of smells, yes, I mean other scents perhaps not. (Right) I mean I often permanently have had all sorts of colds, a blocked nose, I mean for long periods of time I can smell very little at all but that I always find [sweet smells] overpowering even when it's not been particularly strong.

Participant D also suggests a heightened sensitivity to the specific smells of disinfectant and the smell of burning in the environment in concentrations which would not be detected at all by others. Indeed his account suggests some lack of confidence in the reality of these olfactory experiences:

D: Sometimes I smell things that aren't there. ... I don't know, if they're not there, it's just in quantities like, I smell disinfectant quite a lot of time and lots of other people can't smell it. (Right) Sort of chlorine things. ... Yea, and sometimes I can smell certain things, like I particularly smell things burning but nobody else can. Maybe,[something burning] I don't know, nothing in the immediate vicinity.

### **Hypo-reactivity to smell**

This category relates to descriptions of under-reactivity to or lack of awareness of smell. Participants B, D and G recalled situations in which they were unaware of smells or types of smell of which other people were aware. Participant F attributed instances of hypo-reactivity to a long history of sinus problems throughout his childhood.

Participant B describes an example of his lack of awareness of a particular odour until his attention was drawn to it by others:

B: I think sometimes people used to say "Oh, can you smell that bleach, it stinks. I really hate the smell of that bleach." And I'd say actually I quite like it. (Right) Umm, but had they not told me I probably wouldn't have noticed.

D: Sometimes but sometimes I don't smell things that to other people are obvious.

G: I wouldn't notice things that if they thought someone hadn't washed and smelt unpleasant or something was dirty you know just hadn't been cleaned, because I wasn't bothered, to me smell was quite a neutral sense (right) like touch some of the time, then that was just the same.

### **Evocative smell**

This refers to descriptions of olfactory experience impacting on or being influenced by the context or situations with which it is associated.

Participants B and G explicitly refer to strong associations between smell and its associated contexts:

Participant B suggests that his emotional response to situations can be strongly influenced by smell including those of which he is not consciously aware:

B: Smells can stir up very strong emotional responses umm.... Well, sometimes, the whole atmosphere, everything I'm feeling, everything I'm thinking and all the people around me and everything that's going in visually and auditorily, everything, umm... the whole, the whole feel of it can be fundamentally affected by the smell, the smell of the room at the time, without me actually being aware, without me actually being aware of it - do you understand what I'm say? (Yes) So, if the room had an unpleasant smell to it, if the room smelt of sweaty feet or something like that, I would not necessarily umm, I would feel like I didn't really want to be there, without actually realising that the smell was the reason behind it.

Conversely he suggests that his subjective evaluation of smell as pleasant or unpleasant can be influenced by its association with particular contexts:

B: Umm, I think maybe generally there are pleasant smells and there are unpleasant smells - and also like umm, some smells have very strong associations when you're..umm..... I mean there was a time when I didn't used to like the smell of coconut but I now quite like it. ... As I've grown up a lot of things which I used to hate I've actually grown to quite like (right).

Participant G indicates that for him the emotional context can effect how smell is evaluated either as pleasant or unpleasant:

G: Umm, not much as a child, umm, well yes, because when we lived at the Meeting House, we had a lot of animals, there was a lot of manure so I enjoyed the smell of that which was very unusual because it, often on a school trip I used to like it 'cos it reminded me of being at home and I was always slightly

uncomfortable being on a trip away from home but when we drove past a farm I mean other people would think it unusual but I'd like the smell of that.

Participant B describes strong olfactory memories associated with familiar people and places:

B: Ummm, things that I've, smells that ummm, smells that I associate with things... I suppose every house you go to, every ummm has a smell of its own (right). There are certain smells I associated quite strongly with grandma's house, other smells I'd associate much more with umm, I mean the car had a smell of its own (uhum). There was a "daddy" type smell!!! umm, yea, everything.

## **Taste**

Two main factors can be identified from participants accounts as influencing their eating behaviour and experience of taste.

### **Preferring the familiar**

In describing their experience of taste a number of participants referred to a childhood concern for familiarity and sameness and a difficulty in negotiating change, variety or the unfamiliar. This included familiar/unfamiliar tastes and combinations of foods.

Participant F clearly identifies a dislike of eating vegetables as due to difficulty in dealing with change rather than anything to do with taste or texture per se:

F: If I'd eaten vegetables when I was little I probably would be able to eat them ... I think it's just because I've never had them. (Right) I can't get used to it really .

Similarly, Participant F describes checking his food in certain situations so as to avoid unwittingly experiencing new combinations of food together:

F: I think I sort of have to know what I'm eating because if I sort of get a forkful or err meat and there's lettuce there, I sort of have to take the lettuce out or sort of not put the lettuce in my mouth because that would be awful and I'd have to go and kill myself if I did that! ... I think it's because I've never done it before-change again.

A process of becoming familiar with a greater variety of food is described by Participant E as the main development in his experience of taste since childhood:

E: As a child, there were things to become familiar with. ... It's a problem for any child.

A number of participants describe a childhood insistence on particular food items. Participant C liked gravy with most cooked foods while Participant F went through a phase of 'bananas with everything'

C: I used to have gravy.... I just used to have it on a lot of cooked things. ... there was a time when I also used to like tomato ketchup on things as well.

Participant C reports that he has now overcome these food rigidities and food preferences are now more socially normative:

C: No, I just like gravy occasionally on joints of meat.

### **Social influences**

Participant B recalls how social reaction while perhaps not causing them, contributed to maintenance of unusual food preferences in childhood:

B: actually, strangely enough, I used to like eating raw onion and raw lemon, very unusual I suppose and people would be saying ' Are you sure you can eat that?' and it sounded to me like they were saying umm 'Are you strong enough to be able to take that?', so that would make me want to eat raw lemon even more.

Participant F describes the role of social factors in directly influencing diet and development of a greater range of acceptable foods as he's got older:

F: ... I ate green beans for the first time at the Early years Centre. I wasn't sort of not going to eat them because I was sort of in a very big

social environment and didn't want to sort of embarrass myself by not eating vegetables.

F: Umm, I like banana yogurt and Weetabix but that's probably because there's a programme called "Rainbow" which I watched and one of the people on there liked to eat it and I thought 'I could be like them, I'll eat yogurt'.

## **Body Awareness**

### **Body state awareness**

This category relates to participants descriptions of internal bodily sensation and drives. It includes awareness of pain, temperature, hunger and thirst.

### *Variable Experience of Pain*

All participants describe variability in their experience of pain. This variability ranges from descriptions of 'normal' pain reactions to apparent hypo-reactivity in some situations to hyper-reactivity in other situations.

D: I can remember once over-jumping a mat in PE and I hurt my ankle. It hurt quite badly, I think it was just badly bruised, it hurt quite a lot when I landed but it sort of subsided. ... I screamed a bit.

F:... Like when I went in for my operation on my head, the recent one, it was the most painful head operation you can have and they were saying "F, take lots of morphine because it must be hurting like hell" and it wasn't hurting. It was very strange.

G: Feeling pain's very strange for me because at times I can have hurt myself quite severely, broken a finger, and not noticed it at all and yet at other times something could be quite minor, bang myself and not even bruise or sort of break a finger nail slightly, and I can be in agony and think I'm absolutely dying...

### *Hypo-reactivity*

A number of participants descriptions suggest that attentional awareness may be one factor which plays a key role in the variability of their pain experience. With regard to hypo-reactivity, Participant G suggests that for many types of pain it may be necessary for him to 'see' damage or injury



before pain sensation from the affected area is attended to and even then this sensation may not be clearly experienced or labeled as pain.

G: Yes, that's right, that's quite, often if I've damaged myself in some way, I don't notice until I look at it (right) and then I feel something or other, not always pain but of something. (OK, OK). I think that's very true, that if I don't notice it, it's not there until I see it.

Participants F and D suggest a degree of voluntary control over what is experienced as painful and the ability to 'screen out' pain sensation from awareness:

F: Yea, if I allowed myself to feel pain, if I stuck a pin in myself and said this is going to hurt now, I would feel it. But if I sort of stuck it in myself and said this isn't going to hurt, it would be all right.

D: ... and once in secondary school I banged my knee and got a huge swelling. It didn't really, yea it did hurt, but it didn't really bother me 'cos I sort of screened it out.... I just ignored it, and I thought about something else.

F: I've no idea... if someone sort of tickles me I can sort of just stop. I don't really know. If I, like when I had the top of my thumb cut off.. ummm that, initially when it came off I thought Oh my God it's going to hurt loads but it didn't hurt that much because I think I stopped myself from feeling the pain.

Participant B suggests that a sense of shock or disbelief distracted him from an awareness of pain in certain situations:

B: ... There are times when I've fallen over and grazed my knee or broken my tooth, that kind of thing... I don't think it was really the pain that bothered me... it was how it happened I suppose, and when the front of my tooth broke I was saying to the school nurse " it just

feels really strange that his has happened" and she said "Doesn't it hurt?" and I said "I'm not really feeling about it hurting, it's just well this kind of thing has happened in my dreams a few times but it's never actually happened in real life before". I almost felt like pinching myself because.... Yes that almost took my mind off the pain - the disbelief!

### *Hyper-reactivity*

Participants however, also describe a degree of hyper-reactivity to specific sources of discomfort. Participant F describes a strong and overwhelming reaction to needles. Participant G indicates that pain associated with nails or mouth is experienced as intensely painful:

F: ... Needles is the one thing I cannot stop myself from feeling, it REALLY hurts - well, it's not that it hurts, it's the sense of a needle going into my skin, it doesn't agree with me (uhum) especially at the doctors.

G: ... the two pains I've never coped with are damaging a finger nail or pain in my mouth that's like toothache or something.... but to damage a fingernail, just to break a nail or something or to have chewed it and it starts bleeding, I just don't like that, I can't cope with that sense of pain at all.

As in Participant G's earlier account in relation needing to see damage in certain situations in order to notice the associated discomfort, the above description by Participant F of his reaction to needles suggests some lack of clarity as to whether or not the resultant sensation constitutes 'pain' or something else. This sense of difficulty in articulating or labeling the exact nature of what is experienced is mirrored in other situations:

F: ... I think, it [walking around with a broken foot for seven weeks] wasn't painful exactly, it was just uncomfortable, sort of hitty a bit, it sort of just twinged but it wasn't, didn't bother me.

Participant G suggests that poor memory contributes to a difficulty in correctly labeling pain and illness. As a consequence he may become over-anxious and over-react to common or minor aches and ailments:

G: It's sort of not having a memory. I've had a real problem with illness 'cos I can't remember what it's like to have a cold before so I wake up in the morning and have a blocked nose and a headache and not know what's wrong and think I'm completely ill and can't possibly go to school and it's taken a lot.. I mean my parents suggested that I used to write down what I felt like, so that you know, I could record it and remember, mainly from other people telling me that it's only a cold, that it's not serious 'cos I would think I'd never felt like this before and it was the worst thing that was happening.

A number of participants highlight the role of social experience in mediating their reaction to pain. Participant E describes a gradual toughening up in middle childhood:

E: Well I think I was more reactive and more sensitive than most kids when I was very small (right) but gradually I learnt to ignore it. ... I think I remember being less able, certainly when I was seven I was probably less able than the other kids to take being battered about a bit. (Right) But gradually I toughened up and became more normal. There were things, to people mostly I came across as being sensitive and (uhum) so the victim (right)

\*R: So you might have showed your pain more than other children?

E: Yes. ... I used to be frightened of the other kids and often went, withdrew into my own world. ... But gradually as I got older, when I got to be nine or ten, I was one of the lads (right) and I think by then I was accepted more often and I seemed to be more tough than I was before and if I got hit in the face by a cricket ball I didn't cry so...

Similarly Participant G indicates a gradual desensitization to pain as a result of physical bullying in childhood:

G: Yes, yes, I mean I think that part of the desensitization to pain came through being physically bullied a lot. Being hit a lot perhaps didn't deaden the nerve endings but built up a tolerance. I mean I've always consistently had a high tolerance to that sort of physical pain - banging into things,... that sort of thing, and I think that might have had an effect.

Participant G describes a critical role for mental health or mood state in relation to pain experience and in particular a link between depression and his periodic masochistic enjoyment of self-mutilation:

G: ... But I mean at times I think when I went through a period when I was very depressed, I used to like inflicting sort of pain on myself in ways that it wasn't pain, I used to cut myself, like a razor or something, not to, you know, I wasn't committing suicide, I was just cutting myself 'cos the pain made me feel alive, it made me feel in a certain way more enjoyable. That sort of thing. I don't have that sort of thing now but when I was unhappy I used to enjoy the feelings of sort of self-mutilation, that sort of thing when you cut yourself slightly, that sort of thing.

### *Hypo-reactivity to temperature, hunger and thirst*

One participant, Participant G, describes alongside hypo-reactivity to pain, a lack of sensitivity to temperature and difficulties in recognising drives such as hunger and thirst which is not described by other participants:

G: Yes, I mean I remember umm being not bothered by temperature to the extent that I was quite happy to go into the very cold sea if it was on a holiday or to go around and not be bothered by it. And I think it's

still the same today when we go out on walks when it's windy, I feel happy in a T-shirt and don't think it's very cold.

I mean I've still had, like when I'm really, like last year when I went sledging and my, I hung my legs over the back of the sledge and my boots filled with snow and I didn't realise this and so when I got back to the car they'd gone almost blue 'cos I'd been walking around with boots full of snow all day and hadn't realised. So very external touch I really don't feel very much at all.

Well, yes, that's right, [not feeling thirsty] it's still the same now....Umm, to the point where most people would have a drink with a meal but I wouldn't feel thirsty, well I mean, that's what they say, I think it's perhaps more that thirst was a feeling that I couldn't quite understand, 'cos quite often I can't understand quite what I'm feeling and through ignorance of that perhaps the feeling would go away and I wouldn't, I just got out of the habit of drinking, which became a problem. I still have to remind myself - I mean, my parents sort of with most things, they came up with a system where I would say have a drink when I got up, had one with a meal, have one at this sort of time, but I mean it became quite a problem when I didn't drink because obviously it affects my kidneys. I mean I would just say that they hurt it a bit but they got sort of quite damaged and perhaps my skin dried out a bit like once when I went to school and had to have an injection that the nurse couldn't get the needle in and had to actually physically grind it in 'cos my skin had gone very leathery through just dehydration.

Participant G describes some variability in his awareness of temperature but suggests that this tendency to under-reactivity may have lessened with age and in particular contexts:

G: It's sort of changeable, like the pain thing... I think it's the same with temperature, that at times I'm not bothered by hot or cold in the sense that, it's not like leprosy where you lose contact, but I've been

able to hold hot things for long periods of time without realising. I don't know whether the sensation doesn't reach my brain or whatever or doesn't reach the nerves, sort of externally, that [holding hot things] doesn't bother me at all. But at times, I think more in the last couple of years I've been bothered by cold in that I'd like, I prefer warm to cold, now. It wouldn't bother me but like now I'm perhaps more likely to go and put the central heating on or put an extra layer on. But I mean that's more when I'm sort of doing something that I want to concentrate for.

Participant G suggests however, that his problems with recognition of thirst and hunger remain although his ability to cope with them has improved:

G: I think it's just learning coping strategies that were too difficult to learn as a child but still obviously some people might see it as quite a problem, not knowing when I'm hungry or something, but obviously I realise people have much more serious problems and I think I'm very lucky.

Participant G identifies these hypo-reactivities bodily sensation as a significant problem with regard to personal safety:

G::Ummm, I think it's quite significant not realising by touch whether something's hot or cold 'cos I could damage myself very easily by touch and I kind of, I can 've been walking with one arm against you know a wall or something and scraped the skin off it and I haven't realised it. For personal safety I think that's quite a big problem...

Again Participant G attributes these difficulties to a basic problem in recognition memory:

G: Yes, recognising, like with a cold, I find it hard to remember having felt like this before and putting a name to it, and not quite sure why that should be so.

### *Muscle Tension*

One participant, Participant E described chronically high levels of body muscle tension throughout childhood and into his adult life. In addition to feeling tense and a difficulty in relaxing, Participant E attributes a number of problems and physical ailments to this underlying muscle tension and in addition suggests that it contributed to his social difficulties through an odd gait, posture and facial tics.

E: Well I used to have headaches, I used to be often having headaches which I hardly ever have now (Right). But what that was probably down to is the fact that I had a lot of muscle tension around here [eyes] and here [jaw / mouth] (right) and... As a matter of fact, one of the reasons I used to have problems waking up from nightmares was that the muscles in the top of my eyes used to have a way of getting very tense and they used to clench (right) and in normal people the eyeballs move up when you're asleep but in my case they clench and it was very difficult to wake up (Oh, right) and so I clenched round my eyes here and around the sinuses so I always used to have sinus problems and this continued until only about, until about 1990 or thereabouts when I had Shiatsu and it caused it all to relax.

E: Well I used to be very tense as a child. ... I used to have my foot muscles permanently clenched as well (OK), as well as the problem with the eyes I mentioned earlier.... Well, it was very physical. It also made you feel more anxious plus the fact that it made you come across as weird so (right) it meant others could pick on you.

Participant E recalls that it was not until his twenties that he became aware that he could do something about managing this tension. He describes a major reduction in his level of muscle tension with an attendant improvement in associated ailments. However, Participant E continues to be aware of some residual tension



E: Yes, well I was aware of it because I looked a bit funny but I wasn't aware I could do anything about it. ...I couldn't relax in those days (right). Since that time I've had things like Alexander Technique and Shiatsu and (right) a bit of osteopathic treatment too and (OK) that's made me a lot more relaxed than I was (right).

E: Yes. Yes and I often had to lie down with an aspirin or whatever. (Right) Since I've had all the relaxation training and Shiatsu and osteopathy, they haven't been a problem (Right). I hardly ever have headaches these days. ... I really started getting to grips with it when I was 21 (right). One time I went to the dentist after having neglected it for years and he noticed I was very tense and nervous and he thought I'd probably have to be put out and put to sleep for the duration. But the next time I came to him I'd done a bit of relaxation training (OK) and I seemed to be a lot more relaxed and a lot more able to take it.

E: Yes. Clenching my teeth, I mean people, and when I go to the dentist they say my teeth seem to be worn. Oh there's still a little bit of tension left.

### **Manneristic and Repetitive Motor Behaviour**

This category relates to descriptions of repetitive or ritualistic behaviours involving body movement or activity with or without objects.

All participants described manneristic or repetitive activities and body movements. These included arm and hand flapping or jerking, running to and fro, self-spinning, facial tics, teeth grinding, and fidgeting/fiddling with or without objects:

B: Umm, jerking my arms round perhaps.

C: When I was agitated I used to jump up and down.



E: Well I used to flap my arms around (Right, OK). I used to run up and down and... A little bit [spinning] but usually I just jumped up and down and flapped my hands around.

F: Swinging my arms round a lot I used to do and hitting things errr, errr, gritting my teeth a lot as well.

G: Well, I mean anything - shredding things, tearing up but I mean even holding something and moving it around, just rolling it around in my hand I mean a ball or a marble or something.

Participants indicate that many of these behaviours occurred spontaneously and naturally, often without conscious awareness.

G: I was very fiddlesome as a child whether I was excited or not (right) because for a long time my hands had to be doing something (right), they had to be, even if I didn't know what I was doing, even if I was destroying something that was quite important, I wouldn't realise it so I'd be fiddling with some paper, tearing it up, I always had to move my fingers around for a long period of time.

E: Well, I wasn't always aware of it but - sometimes I noticed I was doing it but I did it just the same. I did it without even thinking about it

C: [Involuntary] Just like a reaction.

F: Yea, they're really just spur of the moment things, sort of I didn't control them or anything, they just happened really.

A number of participants do suggest however, that these behaviors were exacerbated by nervousness, anxiety, agitation or excitement:

E: Well sometimes when I was excited and that sort of thing, I used to do it more. (Right) Sometimes even when I was with people (right) so I came across as being weird.

B: Ummm... when I'm agitated or excited... I suppress a lot of them now.

Participant E explains this behaviour in terms of an involuntary displacement activity:

E: It was just that I had loads of energy and needed to discharge it. ... It felt that I was just discharging the energy that I had. ... It was a general displacement activity, I did it all the time. ... Well, even when I was just thinking, I used to do it.

The concurrent affective experience described while engaged in these behaviours varied from individual to individual, ranging from a neutral experience to a pleasing or positive experience including a calming effect.

B: I think it was quite pleasant, there was a lot going on in my mind and not kind of.. because so many things, I might be watching something that was exciting and because all these thoughts would be going through my mind, they'd come out overtly at the same time. (Right, right) It might be waving my arms round and that sort of thing. ... It would calm me down eventually.

E: Sort of neutral, it was just something I did naturally.

C: It [jumping up and down] would calm me down eventually.

However, only Participant G clearly indicates that repetitive motor movements were purposefully sought out as a voluntary control strategy. His analysis of his repetitive behaviour highlights the calming effect of focusing attention on just one repetitive action and he indicates that he would seek out objects to fiddle with in order to calm himself:

G: Yea, because then I'd ummm it's related to what I was sort of doing with my hands and that happened if I focused on what I was doing with my hands and thought about nothing else just incessantly turning a little ball round and round and round in circles or spinning it or doing something, that was calming.

(Right) Rather than making a noise myself. ...Yes, definitely [sought out]. Reaching for the nearest thing or finding something appropriate that I could you know pull to bits, sort of fiddle with until it was OK.

However, Participant G also suggests that inhibition of fiddling and having to suppress this repetitive activity was difficult and in itself produced agitation. It was therefore in his view a combination of these positively and negatively reinforcing consequences which contributed to the end result of a calming experience:

G: Yes, well I mean if I was told I had to sit and couldn't move my hands, that always felt very uncomfortable, not itchy but they always felt they should be doing something. ... obviously I felt calmer because I felt agitated if my hands weren't doing anything but also it was having something to do with my hands, without even knowing it.

Participant D's description also suggests a difficulty in keeping his hands still and a similar sense of contentment when fiddling with objects:

D: Well, I like to have something in my hands to sort of fiddle with really most of the time.... I mean I can't really keep still all the time. ...it's sort of satisfying me, like I've got something to do with my hands.

In contrast to the link with excitement and nervousness, participants, either directly or indirectly, indicate that repetitive and manneristic behaviours were not generally associated with distress or emotional upset.

F: Errr, not really when I'm nervous or upset, when I'm just sort of, my dad does it as well, when he's sort of sitting at a table or something he'll pick something up and play with it and knocks it on the table a few times, I do that as well...

Participants D and C and E for example report that there was little they could do to alleviate feelings of upset or distress other than to wait; they report a gradual calming with time:

D: No [nothing helps]. It just happens, I just wait.

C: Just calm down eventually.

E: Umm, not really. I used to cry for hours sometimes.

Until specifically taught relaxation techniques Participant F indicates a similar situation:

F: I used never[be able] to calm myself down really but then I went to see a man at Retford when I came here and he told me how to do relaxing techniques, sort of tense yourself up and then let go and be nice and relaxed umm but no I didn't really used to do that.

Participant G does indicate that exercise and fast movements such as running or brisk walking were helpful in alleviating distress but this is not described as repetitive or stereotypic:

G: ... it helped to work it off by doing exercise- go out for a walk or something, you know, run up some stairs or something, use up the excess energy that had built up, that was helpful I think. ... I mean that sort of thing, brisk walking, you know just running up to my room. Movement but fast movement like that.

### Self-spinning

Two participants described the experience of self-spinning but highlighted quite different aspects to its appeal. Participant F suggests that the repetitive activity itself was intrinsically appealing but disliked the after-effect of dizziness:

F: Yea, I used to spin myself quite a lot but I really don't like it now because my head spins and hurts and I don't do it anymore... it [enjoyment] was just the spinning feeling, you know just sort of going on, going round and round and round and round and never stopping but then I used to stop and then it used to be really bad

Participant B on the other hand suggests that it the appeal of the activity related very much to the visual after-effects which exerted a strong intellectual fascination for him:

B: I think I found it, I think when I stopped it was the way, it was what happened afterwards (oh, uhum) that intrigued me, the way everything else carried on spinning even though I'd stopped and the way the whole ground, the whole earth seemed to tilt to about a 45 degree angle and yet no-one was falling down. ... it was the after effects (right) but part of the after effects was the fact that when you stopped spinning, everything, the whole ground starts to tilt and it's making a motion, it's umm, it's constantly tilting and it was as if it was always getting steeper and steeper and steeper all the time but what used to always amaze me was how it never went upside down (right). It was always, the ground was always tilting and getting steeper but in actually fact it was never getting any steeper (right, right!) do you see what I'm saying? I was aware of the motion (right) or I had an illusion that the ground was in a tilting motion but the actual angle it was at would never really change. That was what used to intrigue me more than anything.

A number of participants describe a growing awareness of the negative social impact and consequences of manneristic behaviours. A desire to fit in and not come across as weird led to active suppression and control of these behaviours:

E: Yes. Well as a child I was a bit less conscious of it (right, OK) than I became later. But it sort of makes me seem weird and I wanted to learn not to do it.

B: Well, I can remember the consequences umm to an extent of the way other people used to, not necessarily tell me off, they'd tease me about it (right) and I'd be very innocently thinking "yes, but why not, why shouldn't I". .... I suppose it was because I wanted to umm, I wanted to be like everyone else (right) so umm, yea, because I was so determined, I've always been so determined to get rid of whatever it is that's standing in my way.... I would have to consciously suppress it [when younger].

G: It increases when I'm nervous (OK) but I mean I just think more I realise that there are times when it's inappropriate to be fiddling, it's sort of learning to fit in socially I think.

Nevertheless Participant B alludes to this aspect of his life with some pathos:

B: I think, I think we, I think people enjoy experiences more if they're allowed to express them (Yes) but society just hasn't given me that privilege unfortunately!

It is clear that inhibition of these movements and behaviours has with age and effortful practice now become more automatic for a number of participants:

B: Yea, well, I used to have to actively suppress things but I've learnt to, yea.. Not that long ago actually, not that long ago someone used to keep telling me I'd be fidgeting all the time (right, right). In fact that's

what my first girlfriend did to me, she taught me how not to fidget (oh, right) and umm I think I've been kind of more laid back ever since.... the processes by which I suppress it have become automatic and now I would have to make a conscious effort to undo those, to undo the suppression which I built.

E: Well, slowly I did less of it as I got older but there were still ways I just came across as weird. (OK) I think things like moving (sorry) - there were little tics in the muscles of my face which made me, which were there with me (right) right until I was in my twenties.

F: Not any more I think because I've just, I don't know really, I don't think they would happen any more but a few years ago they might have done, yes.

Participant G however, reports a continuing difficulty in controlling his repetitive fiddling with objects even in social situations:

G: Umm, I still get told I've been fiddling with something while at the table or something. I think it shows more when I'm nervous or agitated because I'm more likely to damage something without meaning to (right) or if I'm sitting down and talking to relatives about something and it's like something that's difficult, they often have to move all the glasses and cups and plates away from me because in turn I'll be fiddling with it, not intentionally going to break it but I'll be rolling it round and they have to move that and as soon as they take the knife off me I'll be fiddling with the fork, so it's from one thing to another.



### ***Cross-modality codes***

#### **Individual variability**

This category represents variability between individual participants in a number of dimensions of their sensory -perceptual experience. It includes: variability in modality preferences and strengths; in the range of phenomena identified; in the extent to which individual participants perceived these experiences to be significant or problematic in their lives, and in the extent to which participants perceived their sensory -perceptual experiences as setting them apart or as representing 'difference' from others. In addition there was variability between participants in their ability to reflect on and articulate the nature of their sensory-perceptual experience. Presented here is a summary of the main dimensions of this variability, including aspects additional to those encapsulated within the wider individual modality accounts.

#### *Modality preferences or strengths*

There was variability between participants in the extent to which they identified particular modality preferences and strengths. Two participants described themselves as primarily 'visual' people, one participant described himself as primarily an 'auditory' person and another as having a 'slight' preference for touch. Two participants identified no particular preferences or strengths.

Both Participant B and Participant F describe themselves as primarily 'visual' people and the visual modality as their preferred or peak skill modality:

B: ... No, I think my visual awareness has always been fairly good, in fact it's my peak skill! So it's umm, maybe where sounds are concerned I've had problems but not where umm, but if something comes within my field of vision I notice it.

F: Yea, I'm more of a visual person.



In contrast Participant G reports a general lack of interest in the visual modality which is not reported by other participants:

G: Umm, well, like I said earlier about how I wouldn't mind being blind because most of the things I do don't involve being visual. I don't have much sense of enjoying things that are visual. When I watch a programme on television I have to listen to it, I don't watch the pictures because it's not... I don't pick up anything from them as it were. I pick up more just by listening to it so I listen to more radio than I watch television. I don't sort of appreciate sight, and colour doesn't mean anything to me.

G: Right, I think visually I have a poor visual memory, I can't I mean reproduce the sight of anything at all or people or faces, I'm sort of very poor at recognising that sort of thing because I can't picture it in my head at all.... I'm aware of it being a problem.... I mean it's just not being able to shut my eyes and see something as a picture, I never see pictures of anything in my head.

Participant G identified the auditory modality as his preferred sense, the modality which he considers himself most reliant on to make sense of the world around him and also the channel which gives him the greatest pleasure. In addition Participant G describes himself as having excellent auditory memory, recall and recognition.

G: Yea, well I think, like I said earlier, I think if I could lose all my senses, I would want to keep my hearing. Because often I can't understand a lot of the information that comes in visually or you know through taste and touch, but i've always been good on hearing.

#### *Range and extent of problematic experience*

There was variation between participants in the range and extent of sensory-perceptual phenomena described. This variation included the range of modalities affected and the extent of intra-modality phenomena. For example Participant G identified problematic

/aversive experiences across all modalities whereas Participant E identified past problems only in relation to touch/texture and muscle tension. With regard to individual modalities, taking sound and smell as examples: Participants E and C described their experience of smell in general as no more or less sensitive than that of others around. Other participants described examples of hyper-reactivity and hypo-reactivity to smell compared to others alongside 'normal' reactivity to smell in other contexts.

Among participants reporting problematic experiences with sound, Participant C had a problem with only a very specific number of sounds whereas others reported more generalised difficulties.

There was also considerable variation in the perceived impact of sensory-perceptual phenomena. The impact of the aversive experience was in some situations circumscribed and limited to the immediate situation. For others these aversive experiences led to anticipatory fear and anxiety and avoidance of situations associated with them. For example, one individual dislike of loud sound was perceived by him to have resulted in restricted social opportunities with peers as he avoided social situations where he might encounter loud sound or music.

F: It wasn't that big a problem, I just really didn't like it but if I had, if I was going on a car journey, then I'd go on a car journey (ahah), because we were probably going somewhere fun like a farm or... I could live with it yea.

G: Umm, in certain ways, yes. Not liking loud music for instance made it difficult for me to get on with other people of my own age, who being very much into pop music they liked to have it on quite loud... I think that's caused quite a problem, it just means I've got less in common with people to talk about.

All participants described sensory events as a source of comfort, pleasure or fascination.

*'Difference' in sensory perception*

There was also variability in the extent to which participants considered their sensory-perceptual experiences as reflecting 'difference' compared to others. Participant E for example suggests that his hearing has always been 'fairly normal' while Participants B, D, F and G suggest either explicitly or implicitly that aspects of their experience of sound were unusual compared to others. Participants B, E and F also suggest that circumscribed aspects of their visual experience and skills may be different to others:

B: My field of vision was often around carpets and that kind of thing and my, and all the angles and the acoustics of the room and all the kind of physical environment, the colours, the designs and everything, that used to register quite a lot in me whereas with other people I suppose their fields of, their visual attention was much more focused on each other and on the people rather than on the actual environment.

F: I can find shapes in things, like mum had this book and it was, had a square and you had to find a shape in there (yea, yea) and I did it sort of first time and mum and dad had been taking half an hour over it and I saw that straight away (Right) Most things like that really. (Uhum) Pattern in a pattern I can see, I don't know really.

E: Well, it was occasional, I think probably more than most kids, but it wasn't that I wanted it [spinning object] most of the time.

Participant G identifies his lack of interest in the visual as a source of difference between himself and other people.

G: Umm I think my lack of interest in the sort of visual side of things is probably quite a major problem in getting on with other people. I mean I know not everybody enjoys art and things but my liking for things to be very black and white, in preference of radio to television, or books to pictures, certainly when I was younger, when a lot of

children are interested in visual things more than others. I think that just caused a slight problem and I'm sort of still not interested in something that's advertising if it's very bright. So it took me a long time to realise that other people didn't think this (right) and I always thought that a world that was black and white and grey would be much better (right). But I quickly learnt not to say that 'cos it wouldn't seem appropriate.

#### *Ability to articulate experience*

A further source of variability between participants identified by the researcher lay in the extent to which they were able to articulate their experiences. For example Participant C was unable to provide detailed descriptions of his aversive reaction to certain sounds in childhood whereas other participants provided considerable detail about these experiences. This variability in ability to articulate experiences was reflected across the sensory modalities.

#### **Vagaries of attention**

This category relates to perceived degree of control over attention and sensory-perceptual experience. An underlying theme throughout participant accounts is that of a diminution of full or automatic control over the focus of attention and sensory-perceptual experience: a sense of being at the mercy of the vagaries of their sensory-perceptual system. As a result there is a strong theme of effortfulness in managing and coping with these experiences to achieve a more reliable system.

This perceived lack of mastery over attention and sensory-perceptual experience is evident across the modalities:

D: ... I sometimes find background noises distracting... Err, it's just if it's a noisy place. Sometimes I find it difficult to focus on what someone's saying to me.... Well, it's just that my attention shifts to something else, sort of, on it's own.... it's just it happens.

F: ... when I talk to someone anyway I normally don't look at them at them because I find that really hard to do. But, so, I just look at anything else, like I'm doing now of course. But ummm, I don't know really, the sort of smallest thing [attracts my attention] for some strange reason, or the table leg, I don't know why.

G: I think the biggest problem with smells is I don't like the sweet smells of perfume (right). When someone walks past me with perfume I have to breathe, have difficulty breathing, which obviously in company is a big problem. I mean I notice it walking down the street or being in a room with people wearing all sorts of perfume I get overwhelmed and I can't cope with it.

B: Yea, and it [contact with ears] used to really annoy me. It used to really bug me when that happened (right) so I used to keep putting water on them all the time to try and cool them down but it didn't seem to work... but umm, it was as if, unless I could get my ears cooled down again then I wouldn't be able to do anything else, or concentrate on anything else.

G: Feeling pain's very strange for me, because at times I can have hurt myself quite severely, broken a finger, and not noticed it at all and yet at other times something could be quite minor, bang myself and not even bruise or sort of break a finger nail slightly, and I can be in agony and think I'm absolutely dying...

This sense of not having full control may lead to a perceived lack of confidence in what is 'real' resulting in further problems:

D: ... Especially one of the problems is that I can hear people saying my name and I'm turning round to see what they want and there's no-one there, it doesn't seem to happen that often but it's weird.... The main problem with that now is that sometimes when people do say my name I ignore them.

F: No, they still do [eyes playing 'tricks']. I mean I'm sitting and I see shadows of people and things and sort of very strange things walk past because when I was talking to you a few minutes ago, I saw something whiz past the window, only very quickly. It could have been a bird or something, and I sort of saw it and anything that sort of goes past very quickly, of just the corner of my eye, I see.

On the other hand, for one participant this sensory-perceptual system contributed to a special skill of hearing without awareness:

G: No, I mean I don't listen out for them but I seem to have heard them if they have said something that's about me 'cos I'll usually comment on it later (right, OK) but I haven't necessarily heard it all the time.

There is a strong theme of effortfulness in coping with and managing sensory-perceptual experience. This is described at a number of levels including trying to manage the system in a moment by moment sense, effortfulness in developing strategies to compensate for lack of reliability in sensory perception, and effortfulness in inhibiting and overcoming negative social consequences.

Participant B suggests that conscious and effortful management was required in order to disengage or prevent himself being drawn into repetitive and predictable patterns and shapes, a skill which has become more efficient as he's got older:

B: no, I have I think a sufficient degree of control over it [tendency to get drawn into patterns] now. I umm, I almost consciously tell myself to let go.... I think I'm quite good at stopping myself now.

Participant G describes learning compensatory strategies to overcome his lack of reliable awareness of hunger and thirst:

G: I think it's just learning coping strategies that were too difficult to learn as a child, but still obviously some people might see it as a problem, not knowing when I'm hungry or something, but obviously I realise people have much more serious problems and I think I'm very lucky.

Participant B describes actively suppressing repetitive motor behaviour in order to 'fit in' socially:

B: Well I can remember the consequences umm to an extent, of the way other people used to, not necessarily tel me off, they'd tease me about it (right) and I'd be very innocently thinking "yes, but why not, why shouldn't I?". I suppose it was because I wanted to umm, I wanted to be like everyone else (right) so umm, yea, because I was so determined, I've always been so determined to get rid of whatever it is that's standing in my way.... I would have to consciously suppress it [when younger].

In general there is a theme of sensory-perceptual difficulties attenuating over time although for a number of individuals some difficulties remain.

### **Emotion**

This category relates to the perceived impact of emotional factors on sensory-perceptual experience. Emotion was strongly identified by one participant as a source of variability in his sensory-perceptual experience and as contributing to a sense of unreliability in the working of basic sensory perceptual processes. Anxiety and worry were identified as playing a role in how sensory events are perceived, in vulnerability to distraction and in the extent to which background sound interferes with concentration to tasks. In other situations where emotional state is more relaxed, information processing and the ability to process information across modalities is described as more efficient.

G: Well, umm, I sort of feel like somebody would be claustrophobic with everything closing in, things seem to go too fast for my eyes and sounds go too fast for me to hear them properly and it all becomes a big blur as it were, and it's a sort of scary feeling.... It happens with visual things as well, yea.



G: Oh my hearing can be very erratic, but just more so when I'm anxious. If there's some reason I'm worried about something, then my hearing can play all sorts of tricks on me, hearing things that aren't there, thinking I've heard something I'm expecting to hear or not hearing something that's there at all.

This can lead to a spiral of negative effects.

G: ... and if I'm worried that it's [being distracted by a sound] likely to happen, then it's more likely to happen. If I'm having a conversation when I think I've got to pay attention to what's going on, I've got to appear responsive, I'm always worried that something might happen that will make me, not lose interest, but switch interest to somewhere else. And perhaps the more worried about it I am, the more likely something is to affect it.

Worry and unhappiness also impact in more general ways including a general loss of confidence and upsurge in fears of many kinds:

G:... but again always when I get worried about something, things can seem to be wrong and I can misjudge. You know I'm quite capable of sitting down and missing something (right) but I mean it's never worrying, a big problem. If I get worried, I'll start feeling unsafe and unsure and things seem wrong...

G:... but like a lot of those sort of irrational fears, they come on more when I'm unhappy. If I'm unhappy I'll sort of insist, got, you know, afraid of everything, afraid of the dark, afraid of small spaces, open spaces, heights, you know don't want to do anything, just want to sit still, just want to sort of sit still and be where I am (right)...

Emotion was also identified by a number of participants as a factor in the perception of specific sounds as pleasant or unpleasant through a process of association. Sounds associated with situations, contexts or memories where participants experienced positive emotions were perceived as pleasurable or



pleasant. On the other hand sounds associated with situations or events or memories which provoked negative emotions such as anger, annoyance or sadness were perceived as unpleasant or aversive.

G: I like the sound of things burning, the slight crackly sound of the fire, possibly 'cos I've been comfortable when I've been somewhere with a fireplace and I've been warm and felt better, that sound I like

B: [disliked] the sound of voices, especially the sound of women's voices (right). That's what it was, that's what it was, 'cos I think I found women's voices quite kind of - intense is the wrong word - but very, whatever it was I was thinking at the time, there was nothing like a woman's voice to pull me out of my little world (right) and start telling me to do something or saying I should have done this, that or the other.

### **Developmental processes and change**

This category relates to participant accounts of the developmental course of sensory-perceptual experiences. A process of change in sensory-perceptual experience is reflected in all participant accounts. The specific course of different aspects of sensory-perceptual experience and the factors which are identified as influencing vary from participant to participant. Overall a general theme in participant accounts is that of some degree of attenuation (but not always) in problematic experiences and in sensory fascinations with age.

Problematic sensitivity to sound and vision, and non-social tactile hypersensitivities are described as more pronounced in childhood. Sensory fascinations are described primarily in the past tense. A number of factors are identified as contributing to this gradual amelioration. A lessening (but not necessarily elimination) of the experience of hyperacuity which may contribute to some instances of sensory problems is described by a number of participants. Improved memory is identified by two participants. One participant identifies an increasing skill in semantic processing and the labeling and recognition of events and thus improved ability to predict or

anticipate the occurrence of sound. A lessening of the intensity of pleasure and curiosity in sensory events is also described.

G: ... I can't hear things that are as far away as much as I used to be able to do. (Right). I mean not to any great extent, I mean I can still hear quite well...

B: I can remember my memory playing tricks on me when I was young because my memory had to develop. I think I was about ten or eleven it had reached the stage where I was able to place things in a methodical order and I could remember the sequence in which events happened, but before then I used to get the sequence of it muddled up.

G: Well, in two ways. Firstly as I got older, I was able to recognise more signs, so was able to place them [sounds] quicker or be expecting them to happen anyway and so that became less of a problem. Obviously when I was young and curious about everything, everything would be sort of unexpected but now less so. But I think there were a large number of sounds that were sort of unpleasant in some way because I found them too loud or you know didn't like them in some way when I was younger.

F: I probably enjoyed sound more when I was, I got more excitement, I mean I enjoy sound now but I probably enjoyed it more then. I don't know why that is.

Increasing social awareness is identified as playing a significant role in how remaining sensory-perceptual difficulties are managed. Social experiences and increasing awareness of 'role' can also be identified as playing a part in developmental change:

G: ... I think I'm just more able to hide it now, I mean I now wouldn't go around with my hands over my ears 'cos I think that would make me stand out like something I might have done in the past...

E: Yes. ... I used to be frightened of the other kids and often went, withdrew into my own world. ... But gradually as I got older, when I got to be nine or ten, I was one of the lads (right) and I think by then I was accepted more often and I seemed to be more tough than I was before and if I got hit in the face by a cricket ball I didn't cry so...

### **Specific perceptual aptitudes and deficits**

This category refers to particular perceptual skill 'aptitudes' or 'deficits' which are identified by participants.

#### *Judging distance, size, depth*

A number of participants make references to their visual perceptual skills in judging distance and/or size or depth/height. Two participants describe difficulties in judging size and distance. Participant D describes problems leading to the misjudging of the size of objects viewed from a distance. He describes a tendency to judge size in a literal way in keeping with what he actually sees and therefore to judging distant objects to be smaller than they are:

D: Usually smaller. Like I went to a power station, I mean we were in the control room about 200 yards from the coolant towers and I thought they weren't very big. There was a sort of a bottom bit, a gap at the bottom, I thought that I was about as high as the gap and it turned out the gap was about 30 or 40 feet high.

D: It looked about a couple of hundred yards away but it was probably further.

D: Well yea, I've not only seen that thing with the coolant towers, the Humber bridge was another one. When I looked at that it didn't seem very big but when you actually got on it, it was huge, the big... have you seen the Humber bridge?

... It's got these huge supports for the wires. I didn't think they looked very big but they were.... And another one's power cables. (Right) 'Cos you know those cross pieces, I thought they were about that big (indicating very small). ... but it seems to happen quite a bit, misjudging size.

Participant G describes a lack of reliability in his perception of size which can lead to misjudgments;

G: Yes, I've got a real problem with perception and judgment of how things are when they're far away and even when I get close. I think that's to do with what part of the brain it is that has sort of sight and perception in, and judgment, (right) how tall someone is, I've no idea when, you know, when they're far, when they're walking towards me, perception of how high a hill is or how big a tree is. ... when someone was walking towards me and at first I thought it was a small boy, then I thought it was a man, and then a small boy again, and when he walked close I saw it was a man. It was the height thing, I was trying to judge it against other things and I couldn't find anything to work out how tall this person was until I could see them close.

Participant D's difficulties with the judgment of size are however, described as confined to distant objects whereas for Participant G the problems are more widespread and include judgment of depth and height and problems with motor coordination. Consequently walking and moving around are described as requiring active concentration:

G: Misjudging things was a big problem as a child, umm, for movement around and jumping, whatever, misjudging distances between things, banging into things, falling over, you know, stepping down steps and things, made me seem very clumsy (right) and I mean I still am to a certain extent, when I try and put something on a table, if I miss it or I drop it, that sort of thing, I can seem quite clumsy, missing things when I pick them up.

G: Oh yes, if I don't concentrate on it, [stepping of kerbs] I mean I will fall over when I'm walking around, I have to concentrate on where I'm putting my feet because if I do it without thinking, I'm likely to sort of trip up, that sort of thing (right). I think that's just a perception difficulty. ... I mean, I don't like stairs but I don't like lifts even more so I do stairs

In addition Participant G describes a fear of heights which has persisted since childhood:

G: I've never liked heights so I don't like looking at something that is high up or being high up, that sort of thing. With heights, if I'm on the ground and I look up beyond a certain height, it all looks a bit sort of blurry and a bit swimming because it's so high up to me, sort of relatively, I don't like that and it's just the same looking down but I don't want to be high up. ... Not being able to see it clearly, and sort of feeling unsafe, vertigo, that sort of thing....

Participant C described a problem with escalators which may be related to a difficulty with judging depth or height. However, C was unable to articulate exactly what it was that he found difficult. However, when asked to reflect on his biggest sensory-perceptual difficulty he rated this problem with escalators as possibly his biggest:

C: I didn't particularly like going down the really big escalators on the London Underground. ... I didn't particularly like the height of those London underground ones. After I got here there's a department store in the city called John Lewis and I got trapped on a Saturday morning at the top of an escalator with a long queue of people behind me. ... I was all right going up escalators, just going down them.

Participant G suggests that 'seeing in two dimensional' affects his perception of pictures and photographs and contributes to a lack of interest in them:

G: I certainly don't like pictures because of their not being real so that they don't look like much to me - photographs, that sort of two-dimensional...

In contrast Participant F describes himself as being particularly skilled in detecting embedded figures: Participant's B and F regard spatial judgment and the judgment of perspective as unproblematic and even areas of particular aptitude or strength:

F: Yea, I think I sort of still am really, I sort of see things maybe ummm.. ah, yes, I can find shapes in things, like mum had this book and it was, had a square and you had to find a shape in there (yea, yea) and I did it sort of first time and mum and dad had been taking half an hour over it and I saw that straight away  
(Right) Most things like that really. (Uhum) Pattern in a pattern I can see, I don't know really.

B: Yea, I'd say I'm kind of like, my judgment is obviously, my judgment of distance is more accurate (right) definitely, umm, my judgment of size, my judgment of everything is more developed (right). I think I've got quite good coordination because I juggle and I learned Unicycle and all of that (yes). I think my spatial awareness has always been good. ...I think my visual awareness has always been fairly good, in fact it's my peak skill!

F: I think perspective has always been, I like perspective! especially in drawing, I have to sort of have to get it right otherwise it doesn't sort of work and I get really upset (uhum) but. ... Mum says I'm very, I can climb up mountains and that sort of stuff and always know where to put my feet (uhum) sure-footed I think she says I am.

*Auditory skills*

One participant identified himself as having very good memory and recognition of auditory events in contrast to poor memory and recognition of visual events and proprioceptive states:

G: I've a very good auditory memory for sounds and I like sounds very much... I like listening to impression shows on radio and TV where people do impersonations of people because I can recognise them so well.... I can hear them in my head often and if I can't imitate someone else's voice I can always hear it in my head so I've got quite an enjoyment of that sort of sound.

G: Right, I think visually I have a poor visual memory, I can't I mean reproduce the sight of anything at all or people or faces, I'm sort of very poor at recognising that sort of thing because I can't picture it in my head at all.

... I mean it's just not being able to shut my eyes and see something as a picture, I never see pictures of anything in my head.

G: It's sort of not having a memory. I've had a real problem with illness 'cos I can't remember what it's like to have a cold before

## **Appendix 10**

This appendix relates to Chapter 5, Study 3. It contains a copy of the Supplementary Parent Interview Protocol. This was used, alongside a modified version of the Protocol used in Study 2, to guide interviews with parents.



## Supplementary Parent Interview Protocol

**Name of Autistic Participant:**

**Address:**

**DOB**

**Parent(s)/ Carer(s) Interviewed:**

**(1) Name:**

**Address:**

**Childhood years full-time living with participant?**

**Years living with participant as an adult?**

**(2) Name:**

**Address:**

**Childhood years full-time living with participant?**

**Years living with participant as an adult?**

**Date of Interview:**

**How**

**Comments:**

Thank you very much for agreeing to meet with me and for making the time available for this interview. You've had some written information from me about the study and we have of course spoken on the telephone. Were there any questions you wanted to ask me or anything that wasn't clear to you from all of this before we start?

I would like to ask you about various aspects of (Name)'s sensory behaviour and reactions both as a child and now as an adult. I know that remembering details from your son's childhood might be difficult because of the passage of time, but also because it may awaken memories for you, some of which might be quite painful. Please feel free to take your time, take a break if you wish or indeed stop altogether if you find at any stage that you really don't want to continue. It's difficult to say exactly how long the interview will take - somewhere between one and a half and two hours I should think. Shall we go ahead?

## SUPPLEMENTARY/ALTERNATIVE QUESTIONS

### General Introductory Q's

- Q. 1 Has (Name) talked to you about his/her memories of childhood?  
( Query details, extent of memories, accuracy)
- Q. 2 Have you spoken with (Name) about what he/she was like as a child?  
( Query extent, details)
- Q. 3 Would you say (Name) remembers a lot or very little about his/her childhood?  
Prompt: Has he ever remembered something from his childhood which surprised you?
- Q. 4 How would you describe (Name)'s memory now as an adult?  
Is he able to remember personal events which happen to him?

Q. 5 At what age did (Name) begin to talk?

Did he use these early words correctly, for the right things?

Q. 6 Can you remember when he began to put words together, to use short sentences?

What sorts of things did he communicate?

Q. 7 As a child would (Name) tell you about things he/she particularly liked or enjoyed?

If you asked him specifically?

And now as an adult?

Q. 8 As a child if (Name) was upset or anxious would he/she tell you what it was about if you asked?

And now ?

### **Sensory Modalities**

#### **Hearing**

Q. 9 Did you have any concerns about (Name)'s hearing when he/she was a toddler or young child?

And as an older child in primary or second-level school?

Q. 10 Did he/she have ear problems as a child?

Was this something he/she suffered from a lot or only occasionally?

#### **Vision**

Q. 11 Did (Name) have any problems with his/her eyes as a child?

And now?

Q. 12 Were you ever concerned about his/her eyesight?

## Proprioception

Q. 13 Did you have any concerns about (Name)'s physical development as a child, his/her coordination or sense of balance?

## General Concluding Q's

Q. 14 Apart from the sensory responses that we have talked about did (Name) have any other fears or dislikes during his/her childhood?

Prompt: Any people that (Name) seemed to dislike or avoid?

Any situations which seemed to distress him/her ?

And now as an adult?

Q. 15 Did he/she have any other fascinations or obsessions other than those we have talked about?

Q. 16 Is there anything that you think I should avoid asking (Name)? Any topic which might upset him/her or trigger an obsession for example?

## **Appendix 11**

This appendix relates to Chapter 5, Study 3. It contains a more detailed account, with illustrative verbatim data, of the analysis of parent accounts than is presented in Chapter 5.

### **Analysis of parent interviews**

The core analytic concept of a disordered attentional system was supported by parent interview accounts. Parents very clearly located their observations of many odd or unusual sensory reactions within an attentional framework rather than at the level of physical or structural abnormalities in sensory systems. Their descriptions provided evidence to support the major analytic categories of a disordered attention beam, of a strong sensory based attentional orientation, and of a perseverative bias. Parental accounts emphasised the emotional or affective salience of sensory phenomena in their sons childhood experience. Analysis of their accounts located hyper-sensitivity within a wider category of 'Faulty Modulation' which also includes hypo-reactivity to sensory events and problems in regulating internal body states. The analysis also identified the effect of emotional state and developmental changes on the working of the attentional system.

#### ***Disordered Attention Beam***

As conceptualised the attention beam is regarded as a dynamic 'spotlight' the intensity and breadth of which will determine what sensations and sensory events enter one's attentional focus or awareness. Smooth, automatic narrowing and widening of this beam is considered essential for efficient processing of and responding to significant events (both internal and external) within the sensory environment. Failure in this automatic, dynamic adjustment is conceptualised as leading to problems in sensory processing and responding. An overly-narrowed beam is seen as leading to a lack of adequate awareness of and response to significant events within the environment outside of the particular event being focused on. An over-widely or diffusely focused beam is seen as leading to the opposite problem: being 'open' to too much, a difficulty in filtering out extraneous stimuli and in selective attending to particular events in order to make sense of them.

Parental report of their sons sensory responses are seen as reflecting an impairment in the dynamic adjustment of this attention beam. Their descriptions suggest both an over-wide focus and an over-narrow focus and a degree of effortfulness in processing information and making sense of the world. This impaired mechanism is particularly reflected in parent accounts of unusual reactions to the auditory and visual environment.

### **Over-wide focus**

Parent report of difficulties in identifying or distinguishing individual sensory events from the wider cacophony of incoming stimulation, difficulties with sensory overload and distress in or avoidance of sensorially busy environments are interpreted as reflecting an over-widely focused attentional beam

Parent F:... I mean he umm, F is very rarely in noisy, crowded situations because he will go to great lengths to avoid them but he umm, he just doesn't, you know he says he can't make out sounds. I'm thinking of the swimming pool actually, we always laugh because he has to take his glasses off and of course it is noisy, not where we go where it's open air, but in an indoor one where we don't go very often. Ummm he says he can't hear anything and he can't see anything 'cos he hasn't got his glasses on. And I think he means he can't distinguish the noise rather than he can't actually hear anything.

\*R; C was unable to see things that other people could see?

Parent C: Oh definitely, I mean, I don't know if it's he couldn't see them, 'cos really he could see things properly, but I think it's just his focusing on them.

Parent B, in reviewing a diary she kept when B was younger, reports B's own explanation to her ten years earlier of the reason for his lack of reaction to sudden loud sounds which again suggests impairment in automatic selective attending:

Parent B: Oh, there's another one here as well (yes) umm, it was difficult to hear sudden loud noises because it was all one noise to him. ...So that's a good one, that's from the horse's mouth about ten years ago.

\*R: OK. That sounds as if he wasn't able to pick out things (mmm, seemingly) from everything that was going on. Was that the sort of impression you had?

Mum: Yes, yes.

Parent C cites examples of the way in which 'prosthetic' support was necessary in order to compensate for this difficulty in C's early years:

Parent C: But actually getting him to understand that things had names was quite difficult to start with. (Right) And I remember sitting in the dark one night and we had a torch and we were shining the torch round the room, he would only have been just over a year maybe at this stage, and we lit it up and [we]he said 'Oh there's the clock' and 'Oh there's the television', 'there's the lamp' and he suddenly [realised] 'Oh yes, all these things have got names' and it was sort of like that, as if something had switched on in his head (Right) and because we were just maybe highlighting that one object (Yes), there wasn't anything else (Yes)..

Parent C: Yes, otherwise he's not looking where I want him to look! (OK) He's not seeing what I'm seeing maybe. We used to try that - I'd say 'Look at that plane' or something and he'd say 'Yes, I'm looking at it.' Ha! 'What colour is it then?' 'Oh yellow.' And you could, you know, he hadn't actually found it until you'd asked him something else about it.

\*R: OK. So something about focusing his attention (yes), visually (yes). He was actually looking for it but not quite sure where it was? Is that how you..?

Mum: Yes.



Other problems such as distractibility and difficulty following conversation in particular situations are also reported:

Parent D: So anything within his field of vision or something different he would just be aware of it

\*R: Right, OK. Are there any situations where that [problems in following speech] seems to be so more than others?

Parent C: I would think it is when the television is on and people, you know, more people are talking (Right). Maybe he's got more difficulty focusing on the wrong person that he's supposed to be listening to. .... he'll just ask you to repeat it. I mean he'd know you'd said something (oh right) but he hasn't latched on to what you said.

### **Over-narrow focus**

An overly narrow attentional focus is reflected in parent accounts of intense absorption in activity, and failure to respond to even quite dramatic occurrences within the sensory environment. Indeed the primary quality reflected in several parental accounts is of narrow, intensely focused attending which strongly characterised their sons responses to the world. This over narrow focus is described as particularly marked in childhood and was recalled by some parents as characterising their child's response to the world right from birth. It is reflected in states of intense absorption, often for long periods of time, and a general failure to respond to other events, opportunities and distractions outside of the particular event being focused on:

Parent F: I did actually put something down about hearing. I wonder what I wrote, or perhaps I didn't. Noise, oh yea, just that when he was younger he seemed to be able to ignore it, yea.

\*R: what about very sudden loud noises, if you dropped something or there was a bang unexpectedly? Would that upset him?

Parent E: Sometimes he didn't take the least notice. I mean there were times, I suppose the only time.. no, we didn't really think he was deaf because his vocabulary was so enormous and he also had a vocabulary, a repertoire of nursery rhymes that he knew by heart- he knew about 70 nursery rhymes, didn't he, before he was three...[Dad: Ritualistically}. Yes, so we never really thought he was deaf but there were times that we could because there was a loud noise that he absolutely ignored.

Parent A: Before I was sort of worried about the autism, I already knew he had this ability to focus[uhum], to be single-minded just on one thing.

Parent E: Depending on what he was focusing on [distractibility]. He was a very highly focused child, whatever he was interested in at that moment, he was likely to stay interested in you know! Chances were that five minutes later he was doing the same thing. There was never a problem of lack of concentration [right, OK]. There was much more of a problem of too much concentration on things that, and that he wouldn't want to stop doing them.

Parent G: Oh that's definitely true 'cos he would easily spend a couple of hours playing with the same thing as a very small child.

Parent B: Yea. Umm, he couldn't hear, like when we were on the beach, and there was this kind of jet screaming overhead. Everybody looked up except B (OK). He didn't, and they were so loud, you know it was the sort of thing where you put your hand over your ears and shut your eyes because there were several of them doing manoeuvres across this beach on the south coast (OK) and he just didn't look up at all, he was too busy playing in the sand.

This failure to respond to sound led for some participants to audiological investigation of the possibility of deafness:

Parent B: Yes, umm, because he, as soon as I took him to the GP at a very early age, they said well we have to have the hearing sorted first because we look at anything else and it was very much up to about the age of four it was hearing tests all the time (OK) which he kept on passing OK. But umm eventually he had his tonsils out and a grommet put in and everybody was coming from different areas and they all said oh he'll be better after this (mmm) but of course it wasn't, it was only one hearing specialist saw him at the centre and said well he's lip reading but his problem ISN'T deafness.

This over-narrowing of the attention beam is described as arising involuntarily in as a result of active engagement with an event or activity. However, particular stimuli such as repetitive, predictable events or activities are described as particularly associated with this state.

Parent D: Yeah sometimes he seems completely switched off as if you know 'I'm reading leave me alone' or 'I'm playing a computer game' or 'I'm watching this programme I'm" you know if you say 'D' the house is on fire but it wouldn't matter [Right] Because he wouldn't react at all right and then you had to go a couple of octaves louder 'D now and then he'd say 'don't shout' and growl back...uh yes sometimes he's completely on in his own little world if you like... [And oblivious] to everything else. ...And as he was I don't think it's intentional that he's ignoring you I do think that he's switched he's switched into whatever he's doing and that's it.

Parent A: Well he was totally absorbed in it [watching washing machine spin]. There was no real reason to stop him watching it, we used to call it Washivision you know.

Parent E suggests that intense focus on repetitive stimuli may have assisted E in dealing with sensorially busy environments thus preventing panic and distress as a result of overload:

Parent E: Mum: I think he liked the fact that there were so many things going round and round,[at a fair] you know [yes] ummm that that would have made up for, I think probably he was very strongly focused on the things going round [right] and therefore could stand the noise. We did have one bad situation where he screamed, where we weren't anywhere near the things going round and round and we were at the back.

The effect of this over-narrow focus ranges from examples of not hearing or responding to delay in responding:

Parent D: You know there's no problem there[with hearing]. He just switches off, doesn't perhaps want to hear what you're saying to him.... And even now if he's in, if he's concentrating on something really hard [Right], If he's on the computer or if he's reading "New Scientist" ., or if he's reading a magazine you'll say 'D'. Nothing. And he'll just, like you're saying it in a tone louder: 'Don't shout, I'm not deaf just concentrating'.[Laugh]. Sometimes he is yes[more attentive], but not always, depends what he's doing you know, the frame of mind he's in at the time or just where he happens to be.'

Attempts at intrusion into this state of intense absorption are described by number of parents as eliciting strong emotional reactions:

Parent F: Oh yes he sort of switches off, and then if you try to break through he gets incredibly angry. Umm you know, you'd really have to go and put your face in front of his and then he really quite cross. ...one of the things that makes F, that very big one, happiest is climbing to the very top and sitting cross-legged on it, up there, just looking out across. He can see for miles and he likes to take himself out you know. and I think he does that mentally as well as physically some of the time.

Parent B: Mum: When he was about, yes, when he was about 12 he got very heavily into his computer and began to work out programming and everything and he was completely in love with the computer and everything else was a complete waste of his time and his sister never stopped talking and interfering, she was always coming up. And he got so irritated with her that every time she came up and started talking to him, he started to growl at her (right), he'd just go "Rrrrrr" like that, and it was as though he would have put his hands over his ears because he was so frustrated with that interruption.

However, salience, motivation and interest are identified as influencing the extent to which 'intrusion' or switching of attention is possible:

Parent F: No, I would say the opposite [to distractible] in a way. It was very difficult to get his attention engaged by anything unless he wanted it to be. No, he wasn't easily distracted.

Parent E: Mum:: It would be an intrusion. You could stop him with something even more pleasurable [right]. You could stop him to, well you might be able to stop him, not necessarily. On the whole you wouldn't try 'cos he was obviously having fun...

Despite this quality of intense absorption and lack of responsiveness in early childhood, parents report apparently paradoxical heightened responsivity to certain specific sensory events and it is this dramatic oscillation between the two that parents cite as evidence for their early conviction that a general lack of responsiveness to sound in the early years was not due to a hearing impairment:

Parent F: It was, yes [like an on/off button], that's what I'm struggling for. There could be all sorts of noises around and he wouldn't hear and then perhaps one sort of noise he would go bonkers about. I think it was the sort of switch between those which convinced me that he actually wasn't profoundly deaf.

In addition 'highly salient sounds' are described as triggering responsivity:

Parent B: Well, I do remember that umm although if you talked to him or tried to get his attention, he didn't look up, umm but he could hear very small sounds like rustling of sweet papers and things, he could hear those all right. He'd be there expecting something, so it was obviously not a hearing problem at all.

This erratic response to the sensory environment is described by parents as most pronounced in childhood. However, a number of parents describe some difficulties continuing into adult life highlighting a characteristic of 'effortfulness' in the way in which their sons process and make sense of the flow of events around.

Parent E: ... but there are also times that people could say whatever they wanted and he didn't seem to hear and still I think that might be true. But then there are times when something triggers him hearing, you know, somebody is saying something and suddenly he is in an argument about it.[right]. So, and he hadn't started off in that argument but he got into a political argument or something like that.

Parent B: Well, I think it's still difficult [response to sound] but he's actually very determinedly made himself umm able to cope with just about anything, just about ANYTHING now (right) but I don't think it comes that easily, I think he has to work at it all the time.

Parent B: Umm, well one to one he would actually kind of look into what was going on, as he got older, and respond and listen, but in a group situation he'd just switch off, yea.

Parent G in attempting to explain why certain noises such as the sound of the vacuum cleaner might be problematic for G:

Parent G: Not really [understanding why], it's only guesswork, unless it's interfering with data gathering 'cos he has to work very hard to gather and process information from all around him and if something's disrupting the pattern of that, but I've no evidence of that.

Factors such as anxiety state may continue to impact negatively on the system and contribute towards variability in sensory-perceptual processing:

Parent F: Umm, the [distressed reaction to] noises close to his head I think is pretty consistent. When he was a young baby and young child, the fact that he could cut them out is consistent. Otherwise it varies, you know, sometimes he will umm, it's a question of whether or not he's engaged I think. Sometimes he's engaged and sometimes he isn't engaged. He really, you really can see now him going back into the Asperger's and he's like two different people. When he's not in the Asperger's, he is coming out more and more. He is one person. When he is stressed, he goes into Asperger's and he is quite different, the way he reacts to stimuli, everything is quite, quite different. So you can't say there is one thing that's true of him, necessarily all the time.

However, in addition parents suggest a number of additional factors which may contribute to a lack of normal responsivity to sensory events. Parents suggest that at times there seems to be a separation of hearing and the outward behavioural manifestation of having heard. A perceived lack of personal relevance or salience of the sound is one factor which is identified as potentially contributing to this. However, lack of awareness of social etiquette around listening behaviours may be another:

Parent G: MUM: Well I think he does ignore things like that (DAD: ?mmm). Because he doesn't take part in the same way that perhaps the rest of the family do, he does tend to ignore sounds outside? (DAD: yes) But I don't know whether it's to do with not hearing them or...  
DAD: Yes, that's more along the lines like a car alarm or something went off (MUM: yes) otherwise he might go to the window and peer



out and if you talked to him afterwards he'd say "Yes, I heard it" but so what? because it wasn't anything to do with him or he couldn't imagine himself having any role in the fact, therefore there would be no reason at the time that he would twitch or anything!!

Parent G: MUM: Oh yes, if he's not interested, I think it's true to say he will not pick it up.

DAD: Yes, if it doesn't fit into his current schemata, it's meaningless.

Parent E: Mum: Not hearing it [speech], but listening to it,..... different. His listening skills were appalling, I mean, you know, ummm, I think in a way they're still not wonderful. He had, he certainly had difficulty tuning into people or attending to you if he wasn't interested [uhum]. And certainly he was complained of at school because he didn't look as if he was listening and I remember his...teacher in his second year at school said 'The thing about E is, I will say 'Now E, what about doing this sum?' you know and he'll look at it but he won't really look as if he's listening to what you're saying at all and you'll give him a sum, even you know if you just say a sum and he won't look as if he's heard what you've said and he'll walk round and round<sup>1</sup> the room and after a bit he'll come back and say 79 and a half and..!' you know, and he's done it, and he's done it right, 'so how can you complain' she said.

### ***Sensory based attentional orientation***

This category refers to parent descriptions of a primary attentional orientation to sensory, physical and non-social events within the environment.

Awareness, interest and exploration are centered on a sensory and physical environment that has significant emotional resonance for the individual.

Attunement to the sensory world is especially marked in childhood. This

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orientation is described within the context of impaired social relating and the absence of the 'normal' orientation to people.

### **Interest in the sensory world**

All parents recalled a strong childhood orientation to the physical, sensory and non-social environment which dominated their son's interest and awareness. Parents describe childhood exploration as centered on the sensory and physical world and a failure of attunement to, and interest in, other aspects of the situation including people and shared social activity.

Parent D: When he was very young, uh there were a cot, he was still in his cot. He used to like the mobile, the way [it went] round, and the shadows of it... he used to often watch the ceiling where the shapes were and look at it and look back up. You know from being quite young he used to be into that, looking at, he do, he does actually have quite a good perception of shadow and light and patterns and things, but he, he did like that as a young child. It was like a farmer and animals... [It] used to go around and play a tune which he liked, a lullaby tune, but he were more interested in the shadows. He wouldn't be reaching out for that, he would be looking at the shadows. .. He would be, that would be a quiet time for him [right, ok]. He wasn't quiet very often but that was a nice quiet time

Parent A: He was always opening and shutting doors. He was never interested in what was behind the door, it was just open, shut, open, shut, open, shut.. all these things

Parent B: Yes. Yes, he often, I mean if people were watching something specific like a football game, I don't think he particularly watched it at all, he was probably too busy just watching other things like the shape of the football pitch or the lines on it or umm or how the roads were constructed... and that sort of thing he'd watch much more, the game would be of absolutely no interest whatsoever.

Parent A: You know, another child in the room where there happened to be something catching the light would perhaps be more interested in the people in the room [uhum] but to him that [light] was much more interesting the fact that grandma and other people were in the room [uhum], it seemed to be the most interesting..

### **Intensity of Interest**

A number of the accounts highlight a single-mindedness in the way in which sensory events were attended to which they considered unusual. Terms such as 'fascination' are used to describe the intensity of this orientation. This intensity is described by a number of parents in terms of a different consciousness or reality which served to separate them from their child:

Parent A: Yes, I've just remember that he was fascinated, to a significant degree you know, otherwise I wouldn't have remember it. [Uhum] I'm never quite sure whether it's because it was qualitatively different or because, I always had this feeling that it was none of these things in themselves were particularly unnatural, I just felt it was the fact that he could focus on them so totally and single mindedly [yes, uhum] that other things weren't as important to him [uhum].

Parent B: His eye contact got much better. He started looking at people umm, sort of around one and a half, two (OK) he was beginning to look at people quite a bit. Umm, but he still had what I call this sort of vacant, pale eyed stare, because his eyes were very light, and he'd just kind of stare and it was like they were reflecting the sky. It was so, it was like he was somewhere else, you know.

Parent C: And we knew where every single 'H' sign, you know, the yellow 'H' signs, were, in the whole of Arnold(?). And you might say 'Oh look at that little bird sitting there' and he'd say 'Oh there's an 'H'

sign over there.' You can't, you could never focus him to look where you wanted him to look.... but he couldn't see things, or he didn't want to see them. We went round a zoo when he was three and he went round the whole time following the yellow brick path or whatever it was, and didn't look at an animal at all. (Right) We'd be saying 'Look at this elephant' or tiger, and he just drifted off.

This intense focus on sensory events is described as excluding social interest and awareness despite even quite intrusive attempts to gain or draw his attention to people that could give rise to a feeling that their approaches were intrusive or disruptive to the child:

Parent A: Mum: Oh yes, as a young child, yes, that would be all that he would notice. [Right, OK] Or if he went in a room and there was a sound, you know, that would over-ride everything else.

Parent B: Yea. It was when he was a new baby, ummm, right from the start the nurses noticed there was something different about him, umm and he just used to sit, all propped you know, and stare into space, a great big kind of stare. Umm, and it was like he was looking at lights and things, or big light things, umm but whereas other babies started to sort of start to make eye contact B didn't do that for a very, very long time and he just used to stare. It was like he was staring through people rather than looking in their eyes, he was staring through people when they put their face in front of him. Otherwise he'd just sort of stare at things, shapes and patches of light (OK), yea

Parent E: Mum: It might be an interruption, if we were interrupting what he was doing, because he was a very , very busy child. [Uhum] And one inevitably, constantly felt that you know we were interrupting him [uhum] doing some project that he had, whatever it might be. I mean he did line up little cars and those sorts of things [uhum],

### **Affective Saliency**

The sensory environment is recalled as having particular emotional saliency in the early years. Sensory events were regarded as being a significant source of emotional experience, and as a source of comfort and contentment which was difficult to deliver through social means:

Parent A: Mum:... He was fascinated by the fact of those kind of reflections on glass [uhum] ummm he used to spend hours watching the washing machine.. things spinning round. Hours and hours and hours, and he used to giggle and laugh [uhum]. Umm...

Parent F: Umm, I, when he was a VERY young baby, very, very young, sort of days even rather than, days and early weeks, ummm he would look fixedly at lights, particularly patterns of lights, umm and the only other thing, well there are a couple of things I remember when he was slightly older. We had a little Ferris wheel that you wound up and it went round and 'dah dah dah dah dee dee di' and he used to love that and it was the only way we could calm him down. And the number of times we have lain in the middle of the night my husband with this thing on his chest and me with F on my chest winding this damn thing up, going round and round and round.

As a result parents describe the continued use of 'non-social' strategies to comfort and calm their children considerably past the stage when this would have been normally considered appropriate:

Parent E: Mum: Yes, I mean it was always difficult to comfort him in those situations but in fact the easiest way of comforting him was to give him a bottle [right] and so he went on having a bottle for ages didn't he? - because it was good comfort stuff you know [right] so WE couldn't comfort him.

Certain aspects of the non-social world are described as a source of particularly intense emotional experience. There is a sense of unrivaled, total

abandonment and joy in these events which continued throughout childhood. Water and the sea are identified as a particularly strong source of joy by a number of parents:

Parent G: MUM: And he's the only member of the family who, in February, walking on the beach would take off all his clothes and run off into the sea!!!

DAD: Until very recently he would do that whenever he saw the sea, whatever month of year it was. (Right) And stay in the sea really, basically, wouldn't he?

MUM: I think that's a touch thing as well, it's not just the sight of the sea, it's the feel of the sea, there's something about water, he has always...

DAD: Mmmm, thrown himself, (MUM: absolutely) absolutely abandoned himself...

MUM: And been.. it was about that, I mean it was total relaxation, pleasure, he really felt free in water.

\*R: Would that be in the sea or in the swimming pool, did it matter where?

MUM: It would be anywhere but especially in the sea (DAD: especially the sea) in the open air, yes.

\*R: Did he spent a very long time in the water?

MUM: Oh too much, until he was going blue. Dangerously..... Oh I've got photographs and photographs of him on the beach because of the water that's all he would be doing, he'd be running into the water, naked!... And it is that, taking his clothes off, he had to be free to be in the water - and in snow as well (DAD: ah yes) - run out into the snow with no clothes on.

Parent A: mum:: Yes, he loves the feel of water round him, he still does to this day [Right]. He'll spend eight hours in the sea, not particularly, I mean he does do a bit of swimming now but ummm ever since a young child on the beach it's [right] been the feel of water, especially moving water and waves [right] umm... I mean he will swim but a lot

of the time he'll just be standing there, now what is it, the sight, I mean I don't know..

Parent F: ... he's loved being in the sea but that's not exactly a surface, literally hours he'll spend in the sea. And he does love, he sort of loves the feel of water, the best thing that F can do is to, if you take him somewhere where there's a little waterfall or water running across the beach, he'll spend days just reorganising the water, we always said he's going to be an irrigation engineer!

A range of other events are also described as sources of immense pleasure:

Parent E: Mum: And the happy, excited version [flapping, jumping] would be watching something on television later on, you know once we got television, umm, watching a spinning top or a penny spinning or something like that. Particular visual things that he liked the look of, sometimes just something like flames in the fire or something of that sort [yes, uhum], ummm, he did it at a rainbow once, he flapped and jumped, oh, umm, waves, the sea, being at the sea. I can remember taking a group of [autistic] children... and that was really funny because suddenly everybody was flapping and jumping! [Ha ha!] including the adults, ha ha ha! Annie [another autistic child] used to flap at bubbles [right] - that would have been the sort of thing that E would have flapped at too [right, yes]. Something like that, flames, bubbles, maybe even clouds, umm, snow falling [yes] and he would be flapping and jumping, and those were very happy things. [Yes]

Parent G: DAD:....I was thinking of the chess clock one (MUM: yes), I mean he plays chess and has played chess in tournaments for quite a number of years and in a chess tournament each game has a chess clock of course which ticks and he has talked very strongly about the pleasure that he felt when he sat in a very large room and the only sound he can hear are a hundred ticking chess clocks (I see) as if his



sensation of that situation is sound-led, I suppose it's about the only sense that's being stimulated in that situation, ha, ha. That's one little anecdote that comes to mind.

Parent E describes how events such as these could dramatically alter E's mood:

Parent E: Mum: ... and I suddenly thought as you've said that, well what about something like 'My heart leaps up when I behold a rainbow in the sky' you know that couple of lines. That doesn't have to be socially mediated, you can be entirely on your own, you see the rainbow and your heart leaps up, you know, I agree with that, it's a wonderful... But I can remember with E there would be a sudden change of mood and he could be in a major, major - not wanting to call it tantrum - but you know a major upset, and suddenly he would see something and it wasn't something he wanted to play with, but something happened that his heart leapt up about [right] you know, and his mood would totally change, and that's strange. There's a poet called Lawrence Learner who wrote a poem about that which I very much recognise but he wasn't I don't think writing about an autistic child, but he was talking about a child feeling miserable and not wanting to go to school today and then suddenly he sees this big red bus and suddenly you know everything is wonderful 'cos he's seen this big red bus, and that's very much the way E was [uhum], that he would suddenly see something and it just totally took away his mood.

However, the emotional impact of the non-social environment was not always positive. Idiosyncratic aspects of the physical and sensory environment were also described as a source of fear and distress at times by a number of parents:

Parent B: Umm, I'm trying to think. Yea, I mean there were certain things that he just didn't like the look of. One of the things he didn't

like the look of was my feet (Ah really). My feet are just quite normal looking feet (yea), they're not webbed or anything! (Ha ha!) He didn't like the look of my feet at all, he said " Put your feet away" and I'd put my shoes on. So he had a thing about my feet. He didn't like the look of spiders or moths at all, or butterflies. He got very frightened about that. He used to get quite hysterical sometimes about them.  
 ... Well he just used to say it was just the look of them, just the look of them.

Parent E: Mum: And then there were some things that he'd have an enormous reaction to that, not just sounds, but visual things as well. I remember dropping an egg and he got the horrors about it, he was absolutely - do you remember that? He was absolutely horrified to see this broken egg on the floor and umm.. He had a similar reaction to a broken cup once - it wasn't him that had broken it and it wasn't, you know, it wasn't to do with somebody's going to be cross or anything like that [yes].. by that time I suppose I was beginning to think of the oddity of it much more.

Parent C: Oh he used to cry, he used to, you know, 'Go and wash our hands' and he'd cry, I mean it took us a long time to work out why he didn't want to go in the bathroom. (Oh right) We didn't know why (OK) and you know, I was sort of watching him and he'd be looking at this light and - this would be when he was about two-ish I should think (uhum).

### **Intensity of emotional response: 'in the moment experience'**

A number of parents suggest a qualitative difference in their sons' emotional reactions to the world which in analytic terms may be viewed as a consequence of a non-reflective, in the moment experience. A number of parents describe accentuated emotional intensity in both positive and negative reactions to events around them:



Parent F: Not really, except that when stuff, when he was younger, when stuff did get through to him, it somehow, again I can only really compare it with my daughter, umm, it's an almost indefinable quality, F does feel things very intensely, umm, sort of across the board.

WHEN he feels things, he feels them

at a terrific level of intensity, so I suppose I'm just, you know that's a sort of perhaps emotional level, umm, so perhaps I'm just extrapolating from that but, yea, I mean you know, I think I said the kaleidoscope, that's fantastic, you know, really, and it comes across sometimes now as naiveté, it's quite touching, you know a great big hairy boy sort of 'Wow, wow, this is cool!' [mmm], so umm...

Parent F: No, I think the only thing I might say is that some of the sensations that F has felt have perhaps been slightly more intense you know, if you know, if you present a certain level of stimulus, F may have felt, whatever sense we're talking about, may have felt them slightly more intensely than somebody else

Parent F: Nno, nno. When he does, you know, if there is a smell or whatever that he doesn't like, he gets pretty aggressive about it. Umm but umm, no I really wouldn't have thought there was anything.

\*R: Does that feel like it's overwhelming for him if he's...?

Mum: I don't know. I don't know. Umm, I don't know why, you know, he will often get very aggressive if there's something umm [pause] very, as he's older now it obviously doesn't come out so much as tantrums, it comes out as umm, err just sort of a general aggressive demeanour if there's something, and it may be that it does feel overwhelming [right] you know with the noise, anything that impinges upon him, whatever it is, whether it's a physical or a psychological thing, if he can't get rid of it, is to I suppose, get very, very tense and it comes out as aggression now, whereas before it would come out as a full blown tantrum.

Parent E: Mum: I mean when you see a child whose obsession is being obstructed, or, who you know had an idea of how something

was going to happen and it's not happening quite that way, and that child is agitated [yes] and I mean parents use the term agitated all the time because it means, they don't use it for nothing, they don't use it because professionals use it [yes], they use it because it means something that is different from ordinary distress [yes], and much worse [yes], and which they can't ummm, they can't ignore [yes], you know, it's not like sort of low level distress or a tantrum or something like that. It may be looking like a tantrum - a parent said to me the other day, a mother said to me the other day 'I don't like calling it a tantrum because that sounds as if it hasn't got any meaning for him' [yes] 'it's much more important than that' and I agree with her [yes], you know, it really gets to the child [yes].

### **Non-reflective experience**

Explicit support for the notion of non-reflective experience and particularly poor self-reflection on feelings comes from Parent A and is echoed by Parent C

Parents A: Mum: He doesn't seem to connect up these feelings he has, ... of restlessness, with anything else, cause and effect, it's really strange [Yes]. We can see it from the outside looking in 'cos it always seems to coincide with something but his conception why he's feeling anxious, I don't know whether he would ever use the word 'I feel anxious' [Right] but he just stops, he just stops sleeping. It usually last a fortnight, each episode but what he eventually says is, you know, he can't easily sort of say what it is that's worrying him, I don't know whether he's even aware that he is worried, he just knows that he's suddenly not sleeping.

\*R: If he was upset or anxious, would he be able to tell you what it was that was bothering him?

Mum: No. No, not really. We used to work very hard on this (uhum),

Parent A suggests that impairment in the ability to reflect on experience gives rise to overly physical or concrete understandings of the world, sometimes leading to irritating physical or sensory events being seen as the primary source or cause of distress or anxiety:

Mum: But it's difficult to know how much that is to do with the actual sound and how much it's just to do with the anxiety phobia, [yes] you know, 'Cos he has always, the original trigger for the anxiety's then sort of got misplaced, because he doesn't, he can't sort of analyse himself and [he'll] think well it's this sound you know, or it's television you know, it becomes generalised in a strange way. I don't know whether that's typical at all really of people with autism.

Mum: Yes, certainly when he's more anxious, he becomes more sensitive to the sounds.

Dad: I suppose part of his external environment which is causing him some anxiety, can be blown up, to "this is why I'm like this" [yes], therefore he wants to have that changed [uhum], and that of course can be changed, why not you know.

Despite evidence for a degree of self-reflection, Parent B describes B's reliance on concrete metaphor and physical imagery to think about and articulate his experience:

Parent B: .... but there was something that he said, when he was 12 he occasionally said he was depressed because he hadn't, because he'd got no future. And he said " it felt like this because things bent the wrong way" and he got the urge " to bend them the other way" (oh right). And he equate equated this feeling of hopelessness with this sort of bend, things bending the wrong way, needing to be bent the opposite way.

\*R: Right, what do you think that was about?

Mum: I think that is about this kind of ummm perception of how things feel umm, you know, bending, that's what seemed the strange thing (yes). That if he could bend it the other way then that feeling

would be released and it would be all right.... Yea, that things had got too far one way and that he wanted to push them the other way again. ... He was just equating a feeling he had with an object (right). That was why I wrote that down, I thought that was rather strange (yes). ... He translated a feeling into a concrete object, that was bent the wrong way.

This concrete world view is also considered to be reflected in the tendency reported by a number of parents to use physical, blocking strategies to deal with unwanted social demands or intrusions.

Parent F: Oh no, he does this [hands over ears] a lot, he was doing it just at the weekend actually, if, he does it like this, but it's nowadays always if you're trying to engage with him and he's very distressed. I don't know that it's actually the sound [OK]. I've never seen him, I've never seen him get distressed by what

I've thought was just a sound. Whenever he gets like this I've always interpreted as being the social thing that's getting to him rather than the noise itself but, yes, he does put his hands over his ears a lot.

Parent G: Ha, [hands over ears] only when, in the past particularly, we've tried to sit down with him and thrash something out, he'll say "I will not listen".

### **Marked in early years**

A preoccupation with the sensory world is described as most marked in infancy and early childhood. Parents B and F both recall it as observable within days or weeks of birth. A number of parents describe their feeling at the time that this orientation to aspects of the non-social environment was in some way different or unusual:

Parent F: Yes, yes, different coloured lights. Umm, he just, when he first came home, when he was only about nine days old, eight days old, nine days old, he was actually at that stage, he'd had a pretty

traumatic birth, but he was wonderfully sort of passive and he just stared at the Christmas tree lights. He just sort of sat in his bouncer and stared at them. And that carried on.

Parent A: Mum: Before I was sort of worried about the autism, I already knew he had this ability to focus [uhum] to be single minded, just on one thing [uhum]. And if that was dogs with wagging tails, or washing machines, or tape, then I just knew that that was different somehow [yes]. I wasn't worried about it initially, I thought that's harmless enough, it's a bit quirky [uhum, uhum] you know, the fact that he likes lights coming on and off so much and, he used to open and shut doors a lot...

Mum: I don't know, it [lack of interest in zoo animals] just seemed very weird!.(Right).That he didn't like any of it at all, and that he wasn't prepared to look. (Uhum)

However, aspects of this orientation such as particular sensory fascinations were also seen as valued and positive attributes

Parent B:... he was fascinated with the street lights every evening, he used to watch them coming on. When they were about to come on, he'd stand in the window and wait and when they came on they were pink and we used to call it " street lights coming on pink for B" you know (oh) and he used to watch them coming on pink, and then he used to wait and he never, he looked at them while they changed to orange into yellow, he wouldn't stop looking until they got as bright as they were going to get. And that was a little ritual (right) and I thought that was nice and that was obviously he was very into things like colour and light and things like that.

Parent A: Mum:: Oh yes. Well now, I'd forgotten this, he used to open the drawers and just feel the clothes. Gosh, I'd forgotten that..... Oh quite young, that would have been sort of two? Very young.... Well it was, I was rather touched by it. I can remember 'Oh, he's feeling'. He

wasn't getting them out or being a nuisance, he was just feeling the clothes that were soft, umm..

Nevertheless the exclusivity of this orientation to the sensory and physical world and in particular the lack of interest in people was also a source of deep concern to parents:

Parent A: Mum: Yes, I mean he didn't particularly, you could go, and like you know he was in the garden just running up and down and not taking any notice of other children there or play equipment, or just picking up a stick and flicking with it, you know I just found it, I just found it so painful to watch the fact that he was just doing that and blanking everything out. So I'd go out and play with him and OK, yes, he'd play with me or with the other child, and you'd look out ten minutes later and he'd reverted to running up and down with the stick. [Right, right] I did find that very difficult to be relaxed with.

This strong attentional orientation to the physical and sensory and non-social world is described primarily in the past tense. Parent B is clear that it is no longer a feature in B's response to the world. However, Parent A suggests that A continues to be drawn to physical and sensory aspects of the environment albeit to a much lesser degree. Others also describe particular sensory experiences or objects as having a continuing emotional significance in their sons lives particularly at times of unhappiness or anxiety:

Parent A: Mum: No, they would be quite distracting but not quite so much.

Parent G: DAD: No. He just, he likes little things that he can carry around with him to manipulate.

MUM: Yes, he's always fiddled with something, he's always got something to play with.

DAD: He will take and hoard little things belonging to the other children if he likes the feel of them, doesn't he? (MUM: yes) - ornaments or bits of jewelry or something (MUM: yes, bits of jewelry)



that he knows belong to Eleanor or something but if he's suddenly taken with something you will find it in his pocket and....

MUM: Yes, treasures. (DAD: yes, little treasures, that sort of thing) But there not any particular texture, it's more to do with collecting something and having it about him, to have something about his person, yes.

Parents G: MUM: Only that he does seem to alternate these moods we were talking about earlier, there are times when he seems quite together and he can control things, and there are other times where, almost I suppose he regresses a bit and doesn't feel so good, and needs the comfort of things that will make him feel more secure.

### **Lack of attunement to people**

This sensory-based attentional orientation is clearly described within a context of an underlying social impairment or lack attunement to people and the social environment. A number of parents either directly or indirectly suggest that anomalous relating to the physical sensory world arises from this social impairment:

Parent A: Mum: He seemed to notice things round about, you know [right]Yes, the movement of cats and dogs that made him laugh which was strange [uhum]. Umm, I'm trying to think of...[pause] he didn't sort of, I mean obviously with not looking at peoples face you know, I don't know whether that's to do with what he saw, his perception, you know. His friend came in, you know, he's got an ear-ring on him. He's obviously just focused on the ear and the ear-ring [uhum]. He would focus on things like that.

Parent E: Dad: I think your visual impressions are mediated for normal people through social interchange as well and it must very different for a child who's got a lack of social interchange... saying 'why' [yes] and therefore it's not so much a visual deficit as a total comprehension deficit which is attached to visual things [yes].

This lack of attunement to people can result in a lack of recognition of people as people: 'special' kinds of objects. Failure in the usual social-emotional interchange may lead to idiosyncratic emotional connections and behaviour.

Parent E: but there's a different kind of memory that he talks about which is for instance not knowing that a particular little girl was not a doll. [Right] And he talks, it was a little girl with long hair, and he liked to play with her long hair, and he would now say 'I gave her a really hard time'. This was in nursery. [Right] Umm, but I remember him saying to me I gave her a really hard time but I didn't know she wasn't a doll' and ummm later on errr he, we had a very strange conversation once about ummm what he thought about his younger sisters - one of them's three years younger and the other is six years younger than him

- and we had a very strange conversation about whether he knew they were alive or not. And he actually said he hadn't known that Joan was alive when she was a baby. Now he treated her quite badly, she's the one who's three years younger, and he treated her quite badly in that he went through a stage of pushing and throwing around that time and he was just getting past the stage of throwing, that was at the age of three, umm but then as the baby grew up he would push her over and that was generalised to other children but it started with her.

Umm, and

that was quite a difficult period. Umm, and he said that he didn't really realise that she was alive when he pushed her over and I remember saying I had the feeling at the time that you were pushing her over to see what would happen and that it was quite impersonal, it was like pushing over a doll, and he said 'yes, that's right, I didn't know I was hurting anybody'.

Parent B: He wouldn't touch other people, no. (uhum) Ah, there was just one thing though - if he needed comforting in any way, if he was upset, sometimes he'd get hold of my arm or any, what he later described as any "plumb arms belong to a lady would do", and he'd



sort of push the arm up like this so that there was a sort of crevice, a bent arm, and put his nose inside this little bit (Oh!) and rub his face onto your bare arm, and this seemed to give him a lot of comfort....  
When he chose to do it, yes. Yes, he was about nine or 10, yea.

### **People touch**

Anomalous social relating is also highlighted in parent accounts of their sons reaction to 'people touch'. All parents except Parent C describe difficulty in their sons reactions to touch by others. The extent and developmental course of the difficulty varied from individual to individual. For a number of parents this problem was obvious very early in life and in one case was noted by parents and others right from birth. However, in another case parents did not become aware of difficulty with affectionate touch until school-age. The difficulties with physical contact described by parents ranged from active avoidance to a lack of responsiveness to affectionate contact:

Parent B: Yes, he didn't want to be touched. The nurse in the hospital said to me " Your baby isn't going to be very tactile" she said, " he doesn't like being held" which was very interesting because he'd only just been born.... He just wouldn't seem to react at all. He didn't necessarily stiffen but he wouldn't relax either. It was like just picking up a doll or something.

Parent B: Well, that's quite easy really. Umm, he didn't want anyone touching him and he didn't touch anybody else. So you could get a quick hug off him now and again if, but it was obviously unpleasant for him and it wasn't something that he, he repelled it so, you know, you tried not to upset him too much (uhum). But he was a lovely little boy and everyone wanted to give him a hug so he didn't really, he spent a lot of time backing off, people would come up and say " Hello B" and he'd back off several paces in case they were about to give him a hug I think! (Oh right). He didn't really like being touched at all. When we had this holding therapy business where everyone was ringing up and saying " Have you tried holding

therapy" and " We're holding so and so for two hours" and I said to B " How would you feel about that?" , just knowing what the answer would be and he said " Oh, it makes my skin creep".

Parent F: He wriggled, he wriggled, I mean he umm if I held him without feeding him. He always had to be on the move, he was either bouncing on your knee, bouncing on your foot or if he was tired then I was feeding him, I fed him 'til he was two, just to give myself some peace and quiet. Umm but if you tried to hold him, for instance watching television, I was sort of sitting here trying to hold him, he'd be all over the place, wriggling, crying [uhum], umm he wasn't, he always had to be active, whatever he was doing [right], he had to be active [right] and umm absolutely nothing. He wouldn't, he wouldn't sort of get comfort from anything, I was really frustrated with him..

Parent F: Well... I wouldn't say that he'd avoid, he just was unresponsive [Right].... Yes, he'd just sort of stand there, you know, and then wobble off and do something else.

Parent D: When he was little, yeah um he'd never been a cud, never a cuddly child like John [brother]was.... Um he wasn't one to come and openly come for a cuddle or a snuggle down... He wouldn't come and get in bed with you and a five minute story like John would... Didn't like that at all

Parent A and Parent G describe a more subtle difference in their sons very early response to affectionate touch. There is a sense of tolerance of rather than a sense of comfort and pleasure in being held and cuddled

Parent A: Yes, you always felt it as sort of on his terms.... He wasn't at all the same as my daughter and my other son, you know. He wouldn't sort of snuggle up in that way, but he didn't dislike touch.

Parent G; MUM: He was quite happy to be cuddled as a child, he could take it or leave it.

These differences in the extent of anomalous reaction to physical affection were also reflected in parent accounts of the effectiveness of social strategies in calming and comforting their children:

Parent B: Yes. I think if he was upset, we'd shove something in his hand like a little book or something, something to hold so that would make any difference. I don't think it did really. If he had a favourite object, we'd give him that if he was upset, not try and cuddle him or anything.... Yes he'd just wriggle and umm it wouldn't really help to try and hold him or cuddle him.

Parent F: Umm, he couldn't be comforted when he was a baby just by holding. Umm I used to feed him, I fed him myself, umm if you just held him, again with my daughter you could make her go to sleep just by cuddling her and talking to her, umm he's just...

Parent A: Mmm. I was just trying to think if, if I can remember whether... I can remember it being quite difficult to comfort him but I can remember times when he'd come up to me and sort of grasp my skirt, you know [uhum], when he was frightened of something - so it wasn't entirely missing. Ummm, I could sort of comfort him.

However, Parents E indicate that for E, problems in dealing affectionate touch from his parents did not arise until around school-going age and continued until late childhood.

Parent E: Mum: Oh yes[bothered by touch]. But then it was interesting because he was very kissy, cuddly when he was little. He was a child who would come and kiss you, a lot, do you remember that? [Yes] I can remember my mother being struck by the fact that he would come and give us kisses [uhum] and then he went entirely off it, but he had three years of being in our bed for an awful lot of the time [uhum]... He did accept cuddles - I can't remember when he stopped having cuddles, when he stopped accepting cuddles, it certainly wasn't

on our part. When did he stop wanting them? There came a moment when he started flinching at cuddles, you couldn't, it was very difficult to touch him... Umm and that went on for about six years - he was eleven I think when, I mean I remember the day so well, when I put my arm around him and for the first time in about five or six years he didn't flinch [Mmmm]. I remember exactly where it was, you know, in the kitchen by the draining board! and I came in and I put my arm around him and errr didn't feel that expected flinch which I normally got.

Parents G suggest that G's 'awkwardness' with affectionate contact became more pronounced as he got older and continues now as a young adult:

Parent G: MUM: Not when he was little, no, but as he's grown up he's become more like that (DAD: mmm) I would say - it's got worse?

DAD: Yes, I would say he's now very awkward with personal contact, even within the family, giving hugs and so on, more so than.. (MUM: There was a time when he seemed quite relaxed) one would expect even given adolescence and all that...

MUM: I mean now, if I..

DAD: He asks for a cuddle, he has, he still asks for a cuddle but when it actually comes to the crunch isn't quite sure how to go about it (Right). I mean he wanted to sit on your knee, didn't he, until..

MUM: Oh he still, he still sits on my knee. But it's something he does, in fact all affection, is something of a process, it's not spontaneous, it's something he has to organise and when he does cuddle, if I put my arms round him, my arms will follow the contour of his body, it will be relaxed, his hands, his arms will actually be away from my body, they will be a bit like a robot's - not quite fitting! and will be quite stiff. But he will give the impression that he's trying the best and that's what he's actually wanting to give but can't quite make it.

Parents describe a range of strategies which they adopted in order to achieve some level of physical closeness. These included: continuing, despite their

sons reaction, to initiate hugs; encouraging physical contact with siblings and using highly motivating activities to achieve physical closeness::

Parent E: Mum: I'd quickly go past him and give him a quick cuddle as I went past and then take my arm away. And every time, he would 'ooh', you know, he didn't want that touch, he didn't want an arm round the shoulder. He couldn't bear it, and it felt very much like he couldn't bear the touch. That was one reason why I started getting him to hold Jo [baby sister] so it may have been around that age, five or six [right], that he didn't want touch.

Parent E: Mum: The only way you could get a cuddle at that time - it wasn't a cuddle - it was sitting on the sofa - 'Nudge up a little bit, come on, nudge up a bit 'cos Joan's coming in' you know, and Joan would come in, and I would be getting close to him [right] because there was a limited amount of space and he would be..... [mmm]. Umm, the typical thing then when you were reading though, he would come and sit close to you when you were reading to him [uhum] because he wanted to see the pictures,

Parent F:... I mean in the last couple of weeks he put his arm round me which he's never done before [right] umm I've always, it sounds awful I've always kept on touching, but I've always, I'm quite a sort of tactile person and I have these, you know he's big and up here now, umm I've always made a point of touching him and hugging him, putting my arm round him but he is VERY untactile in a sort of personal capacity.

Parent D:: Probably yes you say 'oh come on D, five minutes' or 'lets look what we've got here' his inquisitiveness and you know making him do it but he won't enjoy it

Despite difficulties with being held or cuddled, parents report enjoyment of play-based physical contact in rough and tumble play and tolerance of other functional touch:

Parent F: Umm, so he umm, he loved, the thing he just loved, until, I mean obviously not now 'cos he's huge, but until he was about 10 or 11, if he was getting into, you know you could see him getting into a state, that we used to play fights and we'd be trying to push, you know we'd get onto our knees in here, when we were living here, and he'd try and push me over, sort of rough and tumble and rolling around on the floor, absolutely great [yes], really fantastic, and that gave him much more comfort than if you'd sat down and cuddled him [right], or anything like that.

Parent A: He loved rough and tumble play. And I never felt he was cold, you know, he used to.. up and look you in the eyes and, you know, we had these sort of long conversations. OK, they were slightly ritualistic, but I felt, I certainly didn't feel it was cold. You know, he looked me straight in the eye and he loved to be tickled and... I can remember my mother saying, 'He's great but you know it's a bit much'. He'd get a bit rough.

Parent G: DAD: He enjoys rough and tumble type contact..

MUM: Yes, and in that respect he can be much more relaxed and the touching is more, it becomes easier, with the rolling and playing.

Parent G: MUM: Actually, going back to what I said about hugging. When he is deliberately hugging and saying I am now.., I want to hug you - that's very difficult for him but he does have a bit of an obsession with wanting you to sit and watch television with him (DAD: yes he likes that) or do something like that (DAD: where he can be close and sort of in physical contact). Yes, so when I sit next to him on the settee, if I cuddle up to him he can put his arm round me and that will be quite different. So if there's some other reason for it, he can be more relaxed and he isn't stiff.

Familiarity and closeness of relationship are identified by parents as impacting on their sons tolerance of physical contact. Difficulties with



childhood social touch are described as particularly pronounced with people outside of the immediate family:

Parent A: Umm [pause] yes if somebody who didn't know him sort of pulled his hand or.. yes, he very much saved all that for us and any kind of interacting for us. I mean I wasn't really worried about his ability to interact with other people. I remember Mike's mother when she was alive and he was little saying you know 'Does he talk to you?' [Uhum]. I don't know whether it was the physical touch thing, she was talking about language and interacting generally, but umm although it just reminded me that actually all of these things it was with us

[right] and any kind of interaction - physical, touching or speaking with other people would be sort of cut them off - he tended only to interact with us. And I always felt, if people said they were worried or made a comment that suggested you know that he wasn't very friendly, I felt oh they don't know 'cos he's OK with us. [Yes, yes] I had nothing to compare him with then you see, my other two, especially my younger son always engaged in conversation with anybody anywhere, on the street [yes] and, you know, but I didn't 'cos he was the first one.

Parent G: MUM: I think there is a little bit of that [recoil from touch]. I think there is with most people. I think he feels that he wants to be closer to us but has difficulty in actually achieving it. But with other people he's always been a little bit distant in touch, even though he's not had difficulty talking to people. People that - I'll have to qualify that - umm 'cos he doesn't talk to strangers - people that he knows.

Even accidental or functional touch by 'outsiders' is described by some parents as continuing to pose problems into early adulthood:

Parent D: But D just does not like anybody invading his personal space he even sitting he doesn't particularly like going to the cinema because you you know you're touching. 'Cause I mean you are pretty close

aren't you in the cinema uh he doesn't particularly like that he likes to sit on the end of a row so at least he's got one side of him being free

Parent G suggests that G's problems with haircuts and visits to the dentist are as a result of an inability to tolerate people he doesn't know' touching him. This problem with touch is however, bound up with other problems in social interaction which includes speaking to people he doesn't know.

Parents G: DAD: Yes, he was quite happy for us to do it [cut hair] wasn't he?

MUM: He's always been very happy for us to do anything to do with his body if other people attempt to do anything, whether that's the dentist, (DAD: hairdresser!) then there are real problems.

\*R: Has he been able to verbalise what that is?

MUM: That's a touch thing isn't it?

DAD: "It's somebody I don't know touching me." (MUM: Yes) Whether this is still current, I mean, he had to have his hair cut recently and there was an enormous, enormous palaver over it and he laid down all the conditions which had to be fulfilled and... it was sensible in a way from his point of view but it had to be, it couldn't be a hairdresser down here because he had to pass that shop on other occasions and so that person would see him in another context, it had to be a different location, the hairdresser had to be briefed beforehand as to exactly what was going to happen (MUM: and not talk to him) and not to talk to him (MUM: while he was having his hair cut!) - it was all set up, you know behind closed shutters, after hours!

MUM: But the actual haircutting, if it was by somebody else, that was a touch feeling that he didn't, couldn't cope with, but actually our doing things like that is not a problem.

DAD: Yes, he's quite happy for you to do it.

MUM: Yes.

\*R:.... Do you have any theories about what is the problem for him?

MUM: I think he does recoil from something, doesn't he? (DAD: mmm) You can actually see that.



DAD: You can see a direct link to the sensation I think which must be nullified if it's us, sort of cancel it out in a way...

MUM: Well, he always says nobody understands me, nobody possibly can understand what I think and feel but you do more than anybody else so it's as though he's allowing us in to something that is difficult for him in any case I suppose. (OK)

Parent E: Mum:... Having his hair cut was difficult. I couldn't, I never took him to a hairdresser, and I still I mean up until very recently I cut his hair. And still he comes home, at his absolute worst, when he hated us most, it was the one thing that I could do for him that was nurturing [right] and so I did go on doing it I, you know, I wanted to go on doing it because it was a way of touching him really [uhum] and that he would accept me being nurturing. Now this is, I'm talking about age 30! you know umm, I could still do it and so for years and years and years until very recently it was always me who cut his hair.

However, Parent B and Parent D both highlight the (very normal!) impact of onset of adolescence and interest in sexual and romantic partners on tolerance of physical and affectionate contact:

Parent B: Yes, yes, he doesn't really liked being hugged and touched very much by ME but I, but he's had girlfriends and (yes) so that's OK, I think he can cope with that all right.

Parent D: But this is only hearsay because another friend was at the sixth form um conference at Sheffield Arena... she said 'come here' 'what' I said, What she said 'I've seen D today' I said 'where' she said 'at the 'UCAS fair at the Arena'. He was walking round with a girl' I said 'were they holding hands' she said 'yes'

### ***Perseverative Bias***

This category refers to an attentional bias or pre-disposition to repetition, predictability and sameness. A recurring theme running throughout parental accounts is that repetition, predictability and sameness strongly characterised their sons attentional preferences, motor behaviour, object play, and interests throughout childhood. This predisposition is described as continuing in attenuated form into adulthood except in the case of Parent B who considers that her son's great determination and effort have allowed him to successfully overcome this tendency.

This perseverative bias is described as characterising their childrens relating to the world from earliest childhood. Even in infancy a number of parents recall their babies attention being drawn to repetitive sensory events and patterns. These included Christmas lights coming on and off, the shadows cast by rotating mobiles or discs or the dynamic pattern of reflected sunlight.

Parent A: Mum: Oh, I know, yes, one thing that used, I mean he was obviously interested in lights coming on and off [yes] right from the age of one. I mean Christmas was just Christmas Tree lights coming on and off, he used to spend hours looking out of the window, the lights coming off, the lights gone off. 'Cos when the street lamps first came off they were red, and that was very interesting, he liked, that was predictable, you know they would come on and this one's red and that one over the road is yellow [uhum], so he was very interested in lights coming on and off. I can remember as a very young baby when I had him in the sling listening to music, if a disc was on and there was a reflection going round the room [uhum], umm that would catch his attention [uhum, uhuh], more than you would expect somehow [uhum]. He was fascinated by the fact of those kind of reflections on glass [uhum] ummm he used to spend hours watching the washing machine.. things spinning round. Hours and hours and hours, and he used to giggle and laugh [uhum]. Umm...

Active repetitive play with objects, insistence on and enjoyment of listening to music, story or poetry heard repetitively, characterises parental accounts of their child's behaviour and preferences in the early childhood years.

Parent D: He had he had a a Fisher Price shape sorter with four shapes in and he that was his favourite thing for months and months he'd just sit literally putting them in the right place and taking them out it shutting them up and putting them back in again

Parent A: Mum: Yes, yes, he would, tapes of nursery rhymes mostly [uhum]. Yea, and he would just listen to them over and over. I was just trying to remember, I think, did we make tapes together? I used to make up tapes and it was wonderful, he was such a good little boy, you know he'd sit with this tape recorder on and I'd do my jobs, you know he was very, he made life very easy, but I did become slightly uneasy about it 'cos he did spend a lot of time doing that.

Parent E: And then there came a point when we used to bring him into bed - and that came pretty early too, didn't it? In fact we were bringing him into bed very early and we used to lie there with him. But it wasn't enough just to come into our bed or just to have a feed, you know, none of that was enough [Right]. He would want you to tell him poems or sing to him or whatever. I sang to him for hours and hours and hours in bed, very quietly and partly in my sleep. And then after, he wanted, he wanted poems and rhymes and "I wandered lonely as a cloud, both on high and o'er vales and hills and all at once I saw a crowd..', you know!! and I would be saying that poem twenty, thirty times every night. He doesn't remember it now- I'm so cross about it [laugh]'cos I think he might have remembered it! Umm, and I would finally think 'Oh he's asleep and I'd stop and then he'd say" more daffodils' and I'd have to go 'I wandered lonely as a cloud'!

\*R: And did he get upset if you didn't?

Parent E: Oh, yes, he'd have screamed, yes. You couldn't say 'no more daffodils'.

There is also support from one parent for perseverative experience at a stimulus level with Parent B recalling her sons description, years previously, of mental 'echoing' of loud speech.

Parent B:... this isn't now, this is a few years ago, about ten years ago, my friend did some research and I asked B a lot of questions and he said he could hear quiet speaking all right when he was young but loud speaking he said 'I heard what was said lots of times in my mind'.

This tendency towards repetition and sameness in play and interests is a strong theme in parental accounts of their sons play and interests throughout childhood and into adulthood.

Parent B: And then there was the shapes as a little, he had a great interest in various creatures like Snoopy and ET and he used to just cut out little shapes out of paper, but hundreds of them, and they'd all go in the bin bags and he'd spend time collecting things to feed them, like dust, and things to feed the Snoopys. Ummm and it was like he'd had an interest in the character but then he'd just cut that character out, make it his, and reproduce it billions of times and that was an obsession that would keep him busy for hours and hours cutting out all these little shapes, yea.

Parent F: He plays my guitar and he refuses to have lessons, he refuses to learn but he's taught himself a series of very repetitive chords and he just goes up and down these cords, again and again and again, and he does that more than listening to his CD's.

Parent B sees the thread of repetition which was expressed in motor behaviour as a younger child as continuing to characterise her sons interests and preoccupations in later childhood:

Parent B: No, I think his interests themselves were the repetitive behaviour and they were really quite complex and interesting... and just the things he liked to do, making Lego cities and plasticine mazes and experiments with ants and things like that, I mean they were all a much more, what's the word, complex version of habits, yea.

Parental accounts suggest a recognition of and respect for the emotional function and impact of repetition and predictability in their sons lives which in childhood they felt it necessary to indulge:

Parent G: Very early on, again it's to do with words and rhythm, I used to sing to him in bed as with a child you have to sing, and that led on to poems as well and he'd have those read to him over and over again, things like "don with the luminous nose" and lots of nursery rhymes and songs from those little ladybird books. In fact to the point where once we got him to -we're talking about 18 months really- stories, short stories, The enormous Pancake and that sort of thing, where he'd have to hear the whole story over and over again and eventually he would be able to, he would know all of the words to all of these, so he found all of that very, very comforting didn't he?

Parent B: Well he did like music and ummm he had a nursery rhyme tape when he was very little which he could listen to over and over again. And he liked classical music as well because there was this passage in Beethoven that he used to sing over and over again, he was only about five, and he used to run along the street singing it, umm which made everyone think he must be some kind of a genius (right), you know! And yes, he really loved music and that was fine. I don't think he liked conversation and listening to people talking because it was too confusing for him so I think he would switch off from words (Uhum) and enjoy music....Well, to be honest I never interfered with it you see (Right). I didn't want to, I thought whatever he's, whatever turns him on, let him have it, don't interrupt him, he became very important, he was first really when it came to all that kind of stuff because I knew how little he was understanding of the

world and thought anything like that was so important, yea.

Predictability is identified by a number of parents as central to the appeal of these activities and interests:

Parent A: Mum: He used to roll balls down slopes, that was one of the things he liked doing. He used to spend hours rolling things, a ball down a slope... we had a little walk-in larder with two steps and he used to roll it down, it used to keep him occupied for hours rolling a ball. But I don't know whether that's 'cause he liked the sight of a spinning ball or the sound of it or just that it's predictable.... There's the fact that it was predictable. I mean, he just, I don't know, I've always had instinctive feelings about why he does these things, but I don't really know. They always seem to be about the predictability of things... you know lights came on, that became the subject of interest for years, you know when the lights came on. 'lights come on now, lights..' You know, it would be ad nauseum, day in, day out, month in, month out, years later the same thing.

Parent C: Thinking about, [Cs attraction to a particular TV programme] and knowing what I know now, it could be the routine of it, that it's always you know (right) exactly the same, you're going to get exactly the same, you get the clock going round (right), you know there wasn't going to be anything surprising coming at you.

A preference for or insistence on sameness and a corresponding difficulty in dealing with change, the unfamiliar or the unpredictable are described as general characteristics which pervaded all aspects of life.

Parent C: No, he's had fads - as I said, the gravy. We went through a stage where everything had to have gravy on it (OK) - whatever. (OK) You know fish fingers had gravy and.. That was when we were going to the city hospital so that would be about five-ish. (Right) When he came out in a rash all round his face and they said maybe he was allergic to having too much gravy! I don't know whether he was or



not!... And we went through grapes, for years and years and years he had to have four grapes on his plate with whatever he was having - roast beef and Yorkshire pudding and four grapes!

Parent G: DAD: What he'd really like with food, he would still tell us I think, is he would like to know that he was having the same meal on the same day each week. If we could work out seven meals for him and he knew Monday was this, Tuesday was that, he says that would be wonderful for him.

MUM: And he also prefers food, he says he prefers food that you can see what it is - whereas most of our food is mixed up in various ways.

Parent B: He was 12 by the time he actually went out on his own to the shop and the whole time he was gone I was really nervous. I really didn't think that he understood anything that would happen that he wasn't expecting. It was just you know, he used to make these mazes and things, and I used to think if life was really a maze he'd find his way to the centre and back, no problem, but because it was so unpredictable out there he just wouldn't be prepared for it. That was it yea.

Parent G: DAD: Generally he avoids the unknown very strongly (MUM: Oh yes). When he leaves the house he's got certain places he will go, he goes to the library in town, and he has his route to the library and back, but I don't believe he would think of deviating from it, or going anywhere else. I mean he has complete freedom to do so, he could browse round the shops and do this that and the other but I'm sure he doesn't, wouldn't, without a specific aim.

This predisposition to repetition and sameness is also be considered to underlie stereotypic behaviour. Although there is variation in the extent to which they are reported as a central feature of childhood behaviour, all parents describe some form of stereotypic motor movements with or without the use of objects, behaviours such as rocking, self-spinning, hand-flapping, finger flicking or running to and fro.

Parent B.: Yes, he also used to run round and round in circles a lot which was a bit like him being a top (right) because they were perfect little circles and he would run round and round and round and round for ages looking at his feet (oh right) and humming. That was also a kind of a spinning I suppose.

Parent F: Umm, he used to bounce up and down a little straight path on his bunny scooter again, and again and again. He used to, as a baby, the only way I could get any peace and I thought all babies were like it until I had another one, I had one of these bouncers that you hang in the doorframe [yes] and if I, I couldn't do anything if he was awake unless, without him screaming his head off, unless I put him in the bouncer and he then just used to bounce, up and down, up and down, all the time. He used to love being bounced up and down, if you stood him even as a little baby on your, or relatively little, on your knee, his knees would go all the time [yes] and he loved being moved up and down, umm, other than that I can't.. he liked, if you pushed the buggy when he was a bit older, over a bouncy surface, he'd laugh his head off [uhum] you know, pushing it over stones and things he thought was great, umm, but the baby bouncer, the thing in the door, hanging him up, we'd say 'Oh I'm just going to hang F up!' [Ha ha!]. He would spend hours just bouncing up and down.

Parent E: Dad: Out in the garden I mean he was often flapping, [Mum: tremendous amount], walking.

Mum: A tremendous amount in the garden and that went on forever. I mean it, eventually it turned into walking very fast [uhum] in the garden! As if you were going somewhere in a great hurry, he'd walk across the lawn, and then he'd turn round in the same way back again [right, OK] and he was doing that in his twenties, still, ummm but a lot of jigging and jumping and flapping and, not exactly spinning himself, but walking in small circles, ummm and stopping to pick a leaf and



roll it up between his fingers, between finger and thumb, and.. what other things did he have?

Parents E highlight what they considered the important "shutting out" role of compulsive repetitive, stereotypic behaviour. Their account suggests parental respect for E's emotional need to withdraw, to become inaccessible to others through stereotypic behaviour. Although finding it difficult to describe the emotional state which accompanied this behaviour Parent E suggests some level of contentment or emotional congruence for E in this behaviour

Parent E: Mum: Which can be used to shut out other things [yes] and I think, I mean I think that's quite an important function. I certainly felt earlier on when E was doing an awful lot of running round and round the table, I mean there was a, we haven't even talked about this, but I mean I'm sure peripheral vision was important in this. He started to walk and then he ran, and he ran and he ran and he ran, and we had dirty marks at each end of the room where he bounced off the walls [uhum] and come back again. And he was a child who didn't so much run in circles, I mean he didn't so much have routes as simply run backwards and forwards and backwards and forwards and backwards and forwards in the sitting room, which was the biggest space you know and umm - do you remember those dirty marks on the walls?

Dad: I can't remember where they were.

Mum: They were at each end of the room where he bounced, he literally bounced off the walls and turned and came back, and when he was doing that and he, there were definite times when he would do it, when he was doing it he was very difficult to get through to indeed, you couldn't interrupt him at all, and part of the time he was like that, he had his hands like that - at the sides of his face and ears - ummm and they weren't necessarily flapping, he would just run like that, so certainly there must have been visual, peripheral vision stimulation there. And it would have been very difficult to say whether he was happy [yes], not actually happy, he was certainly contented with himself [uhum] but it was at the same time

something he had to do. You couldn't have said it was unpleasant, an unpleasant compulsion [yes], it was just something he did, he had to do it, he couldn't do without, needed it [uhum] and it would be hard to give it an emotion [uhum]. And it was very hard to get access to him while he was doing that, to distract him from it, he had to finish it [uhum] and he would eventually finish it.

Parent D notes that repetitive behaviours may be used as a way of calming or relaxing:

Parent D: Because if D's not happy um and he just wants a bit of peace he'll go out there [on the swing]. He looks at this window and he'll be sat swinging up and down.... He'll still go on it. I said 'oh I want to get rid of this 'cause I think Lilly across the corner said, you know when you get rid of your swing can I have it for my grandkids'. He went absolutely awol Right]. He said 'no'. 'My swing that'.... Or if he's feeling stressed reckons he's had a row with John or a row with me if you want to find him he'll be out there swinging up and down.... it does, it calms him down.

However, Parents E also recognised different variations of E's repetitive motor behaviour as reflecting different emotional states:

Mum: No, it felt as if it was pleasurable most of the time. But then if he was agitated, all these things would come in an agitated version. [Right] So flicking and flapping and drumming and jumping, there was an agitated version and there was a happy, excited version. And the happy, excited version would be watching something on television, umm, watching a spinning top or a penny spinning or something like that.... There were three lots of things [Yes] - there was the happy, pleasurable, excited, and there was the ummm really agitated, you know, this is going to build up into a really big scene, and then in the middle, there, well much rarer, but there was a different thing that I recognised as agitation but I also recognised it as an agitation that was going to keep coming back [yes],

it wasn't momentary [yes] and you could see the obsession forming [OK], you know.... He flapped in a bored way just, as well, he wasn't doing things, as though he was just between things and did have a little flap.

Parent E: Mum:... Sometimes it was as if he had to do all that and then at the end of it he would be ready to listen or be engaged with something.

Other parents also 'read' their son's repetitive behaviours as an indicator of mood. A number of parents highlighted the impact of anxiety on these behaviours:

Parent F: Yeea, if he umm, he didn't do much, he used to do a bit of this [flapping] but not very much at all [uhum]. If he's agitated still he does this and sort of rocks backwards and forwards and curls himself up. When he was little, if he was pleased he'd sort of round around very fast, he'd RUN backwards and forwards very fast, other than that I don't think, I don't think there's anything that he does. I don't think, I'm just trying to think what he does now if he's very pleased. He does it more sort of with his voice, he's got a particular voice - patterns, intonations - he'll do, he umm, yea I mean if he is stressed what he will do, I mean this is the ultimate but he will try and get himself way. He'll literally go behind things, he'll run into things [uhum], you know he'll hide behind things but the sort of ritualised movements have always been much more to do with distress. I mean he used to bang his head [uhum], he used to bite himself actually umm when he was younger, they've always been, I wouldn't say they were ritualised movements to do with his being excited, it's always to do with distress that he's shown those.

Parent A: Mum: Yes, more hand-flappy,[ when upset] ummm [pause] I can't remember any particular rituals. But I mean always, eve since he's been little, when he's been anxious he's looked more autistic, you know, finger-flapping, all that kind of thing [yes, yes], most of which

now has disappeared and we only notice it now when he has a bout of anxiety, sleeplessness..

Parents A and E in particular describe stereotypies in the absence of directed activity as an integral feature of their sons childhood behaviour and as occurring unconsciously without apparent awareness. With increasing social awareness and effort these stereotypic movements have been brought under control. However, for A and E this tendency to stereotypy remains, is exacerbated by anxiety, and is still thought to occur in private:

Parent E: Mum: He wouldn't try and stop if it were just a case of not, well it depends when we're talking about, I mean when he was six or seven he wouldn't have tried to stop, or even when he was grown up, if you said he was pacing, he'd say 'I'm not' or something like that, or if you said 'You're rocking'. I remember taking him to buy clothes in Marks and Spencers. He was probably about 18. I know I was paying!! and we were in different parts of Marks and Spencers, sort of wandering around looking at the clothes, and I looked round and there he was bowing at himself in the mirror [right] and, when I say 'bowing' it was like, it was a sort of standing rock really but it involved sort of doing that and nodding his head himself, actually looking at himself under his brows. And that was what he did at home but I hadn't thought he would do it, at the age of 18 I hadn't thought he would do it in public. [Right] But the mirror had triggered it off, ummm, and that really worried me 'cos I thought 'Oh God', you know I thought he'd grown out of that, or I thought he only did it at home. We had quite a lot of mirrors at home and he used to do it, he always used to do it in the bathroom. I used to know the sound of E bowing in the mirror [ha ha ha!] because it involved a rock on his foot, you know rocking one foot to the other, and I could hear him bowing at himself in the mirror, or I knew exactly what he was doing, from outside the bathroom. But that was at least private. But he would, he wouldn't want us to see him doing it, but on the other hand his social empathy was so poor that he

wouldn't realise that we could see him when it was outside the bathroom and he would do it. We had a hall mirror didn't we, and he spent an awful lot of time bowing at himself in that mirror when he was adolescent.

Parent A: Dad: In other words these sort of repetitive, obsessional, ritual activities are probably confined to his own private room...

Mum:... He's not always aware he does the things.

Dad: No, we catch him.

Mum: What was it he was doing?

Dad: It was something like...[demonstrates repetitive motor movement]

Mum: And when I mentioned, I did actually mention it, 'cos you know it seemed a bit odd, he wasn't aware he was doing it.

Dad: But it's still there, my guess, especially when he's anxious, he often used to do it.

Mum: Yes, he definitely does more then.

Dad: We can't prove it.

Mum: Yea, I've once or twice gone in his room and caught him. And the pacing up and down thing, I'm not quite sure what that is you see [uhum].

Dad: The only other thing I've caught him doing, several times, I've gone into my study and he's rather hastily and guiltily put the telephone directory back [Mum: Ohhh] and I don't think he's been looking up a number, to 'phone someone [Right]. He's either looking at numbers or he's being doing this, flicking through the pages [right], obviously looking at the numbers [Dad: Mmm].... Whether it was just the predictability, that I know there's going to be this on the next page or whether it was Oh, I'm going to find a page without a number, and I know what number it should be and then, you know,... or is it just the flicking, I don't know, 'cos he does flick you see, that's another thing.

Dad: And telephone directories are nice and thick, for doing that.

Parent E describes a strategy based on a combination of motivation and developing more awareness of his stereotypic behaviour as helpful in allowing her son to achieve greater control over this aspect of his behaviour:

Parent E: Mum: Well, when he was younger he didn't care whether we saw it or not, anyhow, when he was about six or seven, and ummm but he used to rock in the theatre and that was quite a good way of helping him out of it because it was very obvious, you know he would be doing this sort of thing in the theatre. Now he liked going to the theatre very much, which he doesn't any longer, but he liked it very much then and I said 'Look, I know you know you think it's all right to rock but everybody turns round and looks and they think that you look very strange. And you don't really want to seem strange, do you?' And he said 'Noooo'!. So I said 'Well, if we're going to go on taking you to the theatre I think you've got to learn not to rock while you're in the theatre and shall I help you to learn not to rock because otherwise I don't see how we can go on taking you to the theatre'. 'Cos it really was very embarrassing and I think I would have gone on taking him to the theatre anyhow but I thought well this may be a good motivation. So he said all right, show me how to stop, or something like that. And I did, and what we did was actually the one good piece of psychiatric advice I ever had in the whole of my life ha ha ha! and that was a friend who's a psychiatrist said get him to practice rocking in the mirror [oh] and that will, and you know deliberately to practice it, rather than just rocking in the mirror as he normally did, to practice rocking and stopping and rocking and stopping so that he becomes much more aware of what he's doing and it did actually work very well. It didn't stop him rocking at all but it stopped him rocking in the theatre [right]. Ha ha!... he may still rock, I don't know [uhum] I think he probably still rocks in private. There are times when I think he's rocking in the bathroom - I'm not absolutely certain any longer but, he certainly is much calmer than he ever was. He certainly paces. He does a lot of paces.



### ***Faulty modulation***

This category refers to parent descriptions of faulty modulation in perception of both the internal and external sensory environment. It includes parent descriptions of over-reactivity (hyper-sensitivity) and under-reactivity (hypo-sensitivity) to external sensory events and accounts of anomalous awareness of internal body states and disrupted self-regulation. Faulty modulation is described at two levels: a general level where perception in one or more modalities is described as either hyper- or hypo-acute and a more specific level where (usually) problematic hypersensitivity is described for specific sensory events within one or more modalities.

### **Hypersensitivity**

Support for both the concept of 'general' hyper-acuity and for more specific problematic sensitivity to particular sensory events was strongly evidenced in parent accounts. General hyperacuity can be considered as a heightened or exceptional capacity to detect sensory stimuli: what might be termed an 'amplified' volume or intensity experience within a particular modality. Problematic over-sensitivity refers to a heightened unpleasant/ distress reaction to specific sensory events which may be idiosyncratic to the individual.

#### *General hyperacuity*

General hyperacuity was described in relation to sound and in the case of one participant, smell. With regard to sound, hyperacuity is reflected in accounts of the ability to hear sounds at lower volume or at greater distance than others and as experiencing a given sound as 'louder' than others perceive it.

Parent A: I can remember thinking that he had good hearing. I mean that's why I knew when they said send him for a hearing test, I can't remember specific examples for you but I remember thinking he can certainly hear, better than me in certain cases.... Yes, I know he hears things way before I do [right]. He'll always hear the 'phone or hear a car coming up the drive, rather like a dog you know [right]. Ummm

and he always has been like that. Yes, I've always known his hearing is much more acute than mine. It's just difficult to think of lots of examples for you really [that's fine] but things like the 'phone going in the distance...

Parent D: Yeah probably yeah when if we'd been out [he] said 'why I can hear an engine or a plane or whatever' I said 'well I can't where is it'. he'd say "it'll be over there somewhere" or he'd say things um oh if we were out in the countryside or where, wherever, he'd perhaps sort of say 'have you, did you hear that?' and 'No', mind you my hearing's not a 100% but... He yeah he perhaps does listen to things or.. how can I explain it on a different level than we we would... Um I can't I can't really explain that.

Parents G describe their son's hyper-acuity in more dramatic terms:

Parent G: DAD: It's just a bit of a joke, you can tell by the way we were talking to him, he continues to amaze us. This is a big house, we do tend to have the doors open a lot but he may be 2 or 3 rooms away and there may well be music on as well, and we maybe think we are keeping our voices quite low and he'll come in a few minutes later and quote us verbatim (MUM: or add to the conversation) or just join in as if he has been part of the conversation (MUM: yes) and we continue to be shocked in that we would not have thought, I would still not have thought it humanly possible, even though it's happened a lot, you know a situation will arise quite normally and I will be astounded quite literally that he has actually heard because I wouldn't have thought, I would have thought it would have been impossible in those conditions.

MUM: We might just be dropping our voices talking about something that's happened at work, it could be anything, for whatever reason, just lower the voice and he will just walk in and contribute to the conversation - it's quite incredible.

\*R: Has he talked to you about that, has he described that to you?



MUM: Oh no.

DAD: He just continues as though it's normal really.

Parent G suggest that G's ability to hear sound at this level of hyper-acuity is limited to a specific class of sound, that of voice, because voice is a highly 'salient' sound for him:

Parent G: My guess is it would be voice specific in a way because it's gathering data, verbal data, not just sensory data, but words(mum: yes, I think) which is what he runs on - is words.

Mum: Yes, I think he would be unlikely to hear a train earlier than anyone else because it's not something he would want to be picking up on... Oh yes, he's been tuned into words since he was born, really,[laugh]... it seems like it anyway.

Dad: He'd be oblivious to anything else that's happening around him but process all the words that are going on.

Nevertheless a more general 'amplified volume' experience of sound is suggested in their description of G's dislike of loud music:

Parents G: Mum: We like loud music and we will go into a room where there are a lot of people and very loud music - he finds both of those things very difficult but the loud music he says he cannot - has said, in the past - that he couldn't bear to be in that situation, it was too loud, even though we would say that it wasn't over-loud. I mean, there are times when we might walk out because it's too much, but he definitely finds, even now, loud music difficult but he's tried harder as he grows older....

Parent F also describes dislike and avoidance of loud music or noise which suggests an amplified volume experience. Parent F however, acknowledges the difficulty in disentangling the effect of F's social difficulties from the effects of the auditory environment per se:

Parent F: There's a place near here, an American diner where all the kids think it's fantastic to go and he WON'T go into it, and as you approach he gets like this, and they play loud American music in there [oh right] and he, I'd totally forgotten see, 'I can't go in there, I can't go in there 'cos of my ears. I can't go in there 'cos of my ears.' Now in fact there isn't a clinical reason - a friend of ours now looks after him and he said there isn't actually a clinical reason why he, with his particular ear problems, would find it more difficult than you know Imogen. But he WON'T go in there and he gets in a real state, even if he think you're thinking of suggesting he goes in there [OK]. So umm, and of course he never goes to parties or gigs or anything ummm and he says 'Oh, only because of the noise'. But I don't think that's actually the reason that he doesn't got to parties. But certainly he won't go into this American diner, which is very trendy, big American cars everywhere, because of the noise.

Parent F: Again is it the loud noise or is it that there are lots of young people ? [yes]. I mean if he sees what he calls teenagers in the village he will walk right out of his way to avoid them [right] so it's, you know, you don't know.

With regard to smell, hyperacuity is reflected in the description by Parents A of their son's sensitivity to smell compared to other family members.

Parents A: Mum: He is sensitive to smell now because if Penny's room is rather smelly, he's the one who says it. And on the odd occasion he's told me I smell sweaty or something! [Ha ha!] Umm, he himself is meticulous. He sprays himself all over with Lynx. Now, as a young child [pause]..

Dad: I can't recall knowing, but I think he is more sensitive.

Mum: I think he is much more sensitive to smell, I know he is. [Right] Umm, I'm not a great perfume wearer, but the smells of food, those he would pick up [uhum]. I can't think of any that he doesn't like. [Dad:

No]. Yes, I know, I KNOW he's more sensitive to smell.... Yes, he would always notice [smells outside that others might not pick up on]. I mean if the farmers were putting things on the fields he would notice all that kind of thing [uhum, uhum].

\*R: It's never seemed to upset him or distress him?

Mum: Not particularly.

Dad: He doesn't like....

MUM: No, dog smells.

Dad: He can get irritated by the dog

Mum: Yes, if she's come in wet, that damp doggy sort of smell you get [uhum,

uhum]. I can't remember him actually going up to anybody and saying about their smell.

### *Problematic hyper-sensitivity*

Hypersensitivity is also described for specific sensory events. This problematic over-sensitivity refers to a heightened unpleasant/distress reaction to specific sensory events which may be idiosyncratic to the individual. All parents described some form of problematic reactivity to specific sounds. Over-reactivity in relation to specific aspects of touch and smell was also described by a number of parents.

### Sound

There was considerable variation between individuals in relation to the specific sorts of sounds which were described by parents as problematic. A number of parents suggest that high-pitched or piercing sounds may have been particularly problematic. Several parents reported a distressed reaction to human voice in one form or another.

Parent A: Mum:... Then, I suppose about the same age[three or four], he had a favourite children's television programme called 'Chocobloc' and there as a woman called Carol Cheld who sang, used to sing on it, she had quite a sort of piercing voice, and he loved this programme. I used to sit and watch it with him. [Uhum] And one week this woman sang at the end and he was obviously didn't like it very much [uhum],

but I thought no more of it until it came time to watch the programme the next week and he was really quite agitated. [uhum] And then I remembered you know about this singing the week before, and this built up, so every week when it came near to it, the whole day he would be agitated, the sort of, this programme being on.

Parent B: Well I do remember when he was a very little baby, in his high chair, and I was singing, because I often sort of just hum and sing, and he never took any notice of anything that I did, but I was sat there feeding him, spoon-feeding him, and I decided to do a funny little kind of scale of singing and I went " A, A, A, A, " and his little face broke into sort of terror and he started to cry and he was looking at me and crying as if you know " What was that?" and he really had a reaction to it. (Oh, OK) So umm, then I tried it again a bit later and the same thing happened, he didn't like it.... Which was really interesting because nothing normally seemed to bother him one way or the other and there's this little sound of going up and down on a scale and it frightened him so. I thought that was quite significant (oh right) given that he didn't really respond to anything much at all

Parent F: I'm just trying to think, my mother-in-law tended to sort of give him, oh you know she'd sort of sing balmy songs and keep playing the piano and [yes] he didn't like that. Again it's difficult to know whether it was her he didn't like, 'cos he didn't like her much anyway [yes].

Parent E: MUM:... but later on we thought he was very much affected by the children screaming. He would complain about the children screaming. I mean just ordinary screaming in excitement and the sort of noise that little girls make, you know, ummm...

Mechanical, electrical and loud or sudden noises were also described as triggering distressed reactions:

Parent A: Mum: Well, we never had any, we always knew he could hear really well, umm although he could choose to blank things out. He was very sensitive to certain sound. We had some terrible phobias that came from it actually. I mean, for example, now how old would he have been, umm, we used to eat in the kitchen and we had a fridge that switched itself on, that sort of 'hum' [yes]. He used to really get agitated by that noise when it came on. [OK]. In the kitchen he could be quite disruptive in the middle of the meal.

\*R: How did he react?

Mum: Just shout and cry, this was when he was three/four.

Parent C: He didn't like things like hoovers, drills, vacuum cleaners, mixers, anything.... Lawn mowers, that 'aaaaagh' sort of sound.... He'd cry, and scream, and run away and... It would depend what it was. Or he'd talk gibberish to himself. I'm sure it was him who talked gibberish. He'd sit there in his room talking absolute nonsense, just to sort of shut the sound out.... I don't think that he did [cover ears]. He just used to do a lot of this talking and I'm sure he would have flapped around a bit!!... Yes, very agitated.... because he'd always run, he'd always go to his room.

Parents E: Dad: One I remember in particular was we had a coalhouse as it were [Mum: Yes] and if I was scraping up the coals into the coal bucket, that noise would really get to him [oh right].

Mum: I remember the first time that we really saw that was I actually had him in my, in one arm, because he needed a lot of carrying around!! [Yes] and so we carried him around all the time and I had him in one arm and I scraped up the coal with a shovel [right] with the other hand and he screamed and screamed and screamed and screamed [OK] and was absolutely inconsolable and I thought it's very strange. You know, I mean I understand fear, and I understand shock at suddenly hearing a noise like that, but this was beyond it.

Parent F suggests that physical location of sound was significant in her son's experience of some sounds as problematic:

Parent F: He can't bear, actually that is something, he cannot bear any noise close to his head. He just, he just can't bear it. Ummm, and never has been able to, I mean he reacts almost as though it's a physical pain. I don't know why that it is, I don't know, I don't think that's to do with the hearing loss, I think that's to do with something else. He's never used a hairdryer, he won't. But then he does, of course, he does put earphones on and I get terribly cross with him because ummm you know I say this isn't a good thing to do. So, yes, he wears the earphones but hairdryers, if I you know put my arm round him and sort of kiss him, 'Aaah, terrible noise', so I don't know what's going on there [uhum] because he just, any noise, any noise apart from the earphones, close to his head he really hates.

Parent A indicates that A was hyper-sensitive to a number of barely audible sounds of which other family members would generally not have been aware. This suggests that hyper-acuity may also have played a role in the problematic experience of these sounds:

Parent A: Mum: No, just the fridge, that was a humming in the background [fridge, yes, yes], they were sort of mechanical noises coming off, he would notice them where we would have blanked them out.... Well he would scream 'til it stopped, you know, 'cos it was intermittent, it came on and off.

Parent A; Mum: He used to share a room with his sister. He didn't like the sound of her breathing just as she was going to sleep, the heavy, and he used to go and poke at her. We had to separate their bedrooms in the end, he didn't like the sound of the heavy breathing when she was going to sleep [uhum, uhum], poor girl.

Parent A: Mum: Yes, I've mentioned opera singers, anything like that he, you know, even if it was turned right down [distressful for him].



Actually any cricket on the radio, the voices on the radio even [Dad: Yes].. straining to listen to it really quietly which you'd have to, to pick it out you know, he couldn't tolerate it.

\*R: Did his hearing seem [very acute] very acute for those things?

Mum: Yes, yes.

Dad: Yes, we'd have to have things on very quietly, he would get quite distressed. [Aha] So I couldn't listen to the Test Match in the car when he was in the car [right]. He'd shriek.

Mum: He'd bellow from the back 'Switch it off' you know.

Parental accounts suggest wide variation between participants in the extent to which these hyper-sensitivities impacted on their lives and social functioning. For most distress and anxiety was in their parents view, limited to situations in which the aversive sounds were present. The impact on Participant A and his family was, however, particularly severe because the initial fear of one woman's singing voice on TV generalised into a much wider phobia of all sound through speakers which curtailed his life and that of his family for much of his childhood.

Parent A; Mum: And then it spread to he was afraid whenever a television was switched on. [Oh] And by the time he went to school, when he saw there was a television in the classroom, he was really uptight. And when they had a particular programme on a particular day, he woke up really agitated. We had to sort of bundle him into the car, he'd be absolutely terrified. [OK] But fortunately I realised, traced it, you know realised it was all from this fear of this woman singing. I mean I've talked to him about it since and he can't, he can't say 'Oh yes, it was really painful' or anything, but it was definitely from that woman singing. It developed into full- scale fear, phobia of television, it was really really quite a barrier at school [yes] for two years.

But then it did spread to all music or voices that came out of speakers, and again it was the quality of the voices that came out of speakers

that was different, and that was a huge, terrible, terrifying phobia because we couldn't go to any public place without him immediately scanning the room for hidden speakers, you know, behind umm the ceiling, in shops, in railway stations, theatres, swimming pools. One of the worst times, we went swimming and there wasn't normally piped music there, but we were in the pool and suddenly they switched on this pop, piped music, and it filled the whole swimming pool and I said 'Oh don't worry A, get out, it's all right' so he went out. We'd actually come with friends, he'd got changed in the boys changing room, so he went back to the boys changing room to get changed, and I told the lad who'd come with us to go and make sure he was all right. What had happened when he got to the changing room, it was still there you see [oh right], there were speakers all over, he couldn't escape it, so I had to go and find the people in charge of the swimming pool and explain and they switched it off. We couldn't get him into a swimming pool for years after that. [OK, OK] And it just dominated his life really, for a long time, ummm

Parent A: I mean I can remember [psychologist], he went to some workshops that some of the students were doing, and he was so tense 'cos he was going to a new place and there might be a speaker there and he couldn't relax and benefit from the activities. And it really masked his abilities for a long time 'cos it was such a dominating thing, you know, you can imagine...

Parent A: Mum: I'm sure it was [the sound]. I have talked to him about it but he's not able to sort of lucidly say 'Oh yes, well it hurt me' or anything but he remembers the programme [right, OK] and he remembers that he didn't like it, I don't know whether he can actually get back inside himself to sort of feel it again, I don't know. It'll be interesting to know what he says to you.

But I feel I know him so well, and I just know that it all stemmed from that voice, and there's something about the quality of sound coming out of speakers that is qualitatively different and was very distressing to him.



Parent accounts indicate recognition of, and empathy for, the high levels of distress caused by these sensory events. Parents recognised their inability to allay this distress through normal comforting in the feared situation, and used a range of strategies which recognised their sons need to avoid or escape from unpleasant events.

Parent C: Yes, well yes, either that, I mean you live with it for so long that you take avoiding action, you're ready for it (Right). You know you hear the lawn mower and you're looking and then 'shall we go this way?'

Parent C: No, maybe just be with him, or put on the radio in the room he was in [away from the noise] to try and shut the noise out!

Parent A suggests that lack of control over exposure to the feared sound was a significant element in A's generalised phobic response:

Parent A: Mum: What he couldn't cope with was somebody just switching on the television in case this awful voice came out at him. And that's what he couldn't cope with, about speakers generally in public places because he was not in control of it [right].... It was just the thought in his mind that it would come upon him unawares.

Being offered opportunity for control over exposure to TV or sound through speakers through opportunity for escape or to turn the sound off was described as helpful in helping A to gradually overcome his fear:

Parent A: Mum: But when I told the school what the problem was they said well, when it's time for the programme, we'll let him stand outside the classroom and have the door open and see if he'll sit in the doorway [uhum] and you know, so to begin with he just wasn't in there. As long as he knew there was an escape route, he seemed to be able to cope with things like that. [OK]

Parent A: Mum: No, it's gone now [oh, it's gone, right] completely, but it lasted right through, I mean this all developed after he started school, the thing about speakers generally, the television thing started when he was about four [uhum] umm and he got, that's when we bought a video 'cos we realised that he was, for him to feel he was in control, if he could control, if he could record things and he was in control of it, he could cope. What he couldn't cope with was somebody just switching on the television in case this awful voice came out at him. And that's what he couldn't cope with, about speakers generally in public places because he was not in control of it [right]. So to some extent we had to sort of organise our lives, we tried not to be totally dominated by it, but it set him back such a lot, you know he had to know he could get out and he could choose not to be there if it got too bad.

Involvement in activity identified by Parents E as one factor which mediated his reaction to at least some sounds:

Parent E: mum: Ummm if he had screamed every time the children screamed!! it would have been totally impossible so there must have been times when he was busy and not listening and wasn't upset by them. But we certainly thought it was more than irritation that your younger sister's getting in your way sort of thing. It did seem, we did always think, didn't we? that it was the actual noise that was upsetting him.... Yes he was certainly physically distressed, yes

All parent accounts describe the disappearance of, or significant amelioration, in these hyper-sensitivities over the course of childhood. B's distress at a very circumscribed trigger (Mum's singing in a particular way) was noted only as a baby. C and E's hyper-sensitivities to sound did not continue beyond childhood. Participant A's distress at specific sounds and sound through speakers developed in the pre-school years and continued for several years throughout his schooling. There is some continuing dislike of certain forms of music and singing such as opera. Although there has been some gradual

improvement Participant G continues to find loud music and the sound of the vacuum cleaner difficult to tolerate. Participant F also continues to avoid loud music and noisy situations and continues to dislike noise close to his head.

## Smell

A degree of problematic hypersensitivity to specific smells is suggested by a number of parents. These are described as circumscribed distress reactions to specific smells in childhood which they felt constituted a relatively minor problem:

Parent B: Yea, yea. I don't think he liked bad smells. I think perhaps petrol smells he didn't like very much.... I think, when he was little he'd show some distress. Umm, just kind of go " Oohhh" , just sort of " Oooo" noises really until we rectified the situation.... Yea, I think there were one or twice times when it was the smell that was upsetting him but I can't really remember what it was now, just a vague memory about it. It wasn't really a heavy everyday sort of a problem.

Parent E: Oh I know, he had to have something stitched, he had to have his head stitched.. [uhum] and umm, but it was the same fuss as having his hair cut so you know it wasn't that, it wasn't THAT different. Oh, he hated the smell there, disinfectanty smell of the hospital.... Well he was certainly flailing [right] and pushing things away and 'No, no, no, no'. I seem to remember that he hated the smell of the pad that they wanted to clean his head with [oh]. I mean I could be wrong, it could be just the whole situation that he hated.

Parent D: He didn't like the smell of eggs. At all. He doesn't even like the thought of me frying an egg because of the smell...Yeah he doesn't like smoke doesn't like smoke. He doesn't like going to a smoky room. And if his clothes smell of smoke after we've been somewhere and like say if we've been to the club for a quiz as soon as he comes in he just strips everything off and throws it in the bin... in the washing bin I'm

not wearing it again' ... Yes he doesn't like people smoking around him. ...No he just doesn't like the smell. He feels it's very invasive if you like

### Tactile hypersensitivity

Hypersensitivity is described in relation to specific types of tactile sensation or in relation to specific body parts. All but one parent (Parent C) reported that in childhood their sons showed a strong dislike of wearing certain types of fabrics or clothes such as wool because of itchiness, scratchiness or roughness against the skin. These descriptions suggest that their children's reactions went beyond 'normal' childhood intolerance.

Parent A: Mum: Oh, he didn't like scratchy jumpers. Yes. He wasn't particularly difficult about getting dressed but, yes, certain things next to his skin he didn't like. Yea, I always felt that he was sensitive to feel of clothes. I mean I always used to put little shirts under his jumpers when he was young. He was intolerant to wool I think, although my other children are a bit like that. But I can remember feeling it was more you know?

\*R: How did you realise that?

Mum: I don't know, just 'cos he'd cry or object if you tried to put a certain thing on. It wasn't my most major sort of worry but I suppose because of this, the way he used to feel clothes when he was younger, I just sort of knew he was sensitive to the feel of things.

Parent F: He wouldn't, he still won't wear anything knitted [right].

Absolutely no way, it's too rough. He will only wear cotton, you know shirts [yes] or umm you know sweatshirt-type material [uhum, uhum], ever so fussy about anything which umm this for instance, [pointing to cushion cover] I mean not that you'd wear cushion cover!!, umm but anything that wasn't absolutely smooth, you know he wouldn't. ... it was just that it was rough, it itched him, he said 'it itches, it itches' and that was that.

Parent E: Dad: He's always had worries about putting on certain garments particularly around the neck area [right].

Mum: It's very, very mixed, it's very ambiguous [right]. As a child he would scream if you put a tight jersey on him. He really hated it - most children don't like a tight jersey - he hated it more than most children [right], he really, really screamed. He hated the feel of anything round his neck, he still does [uhum], he doesn't like to have a collar like this, you know polo neck type things he doesn't like [uhum], he wants to be free round his neck.

Parent D: No he didn't he didn't like new things... He didn't like new jeans or new dungarees 'cause they'd be stiff

\*R: Right would he say that to you?

Mum: mmm 'Hard'. [Right]. 'Don't like them'. I mean he's still got I've got he's got a couple of cord shirts up there that he must have had two Christmases ago that he's not worn and I've washed them to get all the dressing and stuffing out of them but he won't wear them. He's got one sweatshirt that he'll wear, one T-shirt that he'll wear I had to literally drag it off him to wash it.

A degree of hypersensitivity (which was finally overcome in adulthood) to both the feel and sound of his arms rubbing against his sides is described by Parents E as leading to negative social consequences for E:

Parent E: Mum: Ummm, for a long time he walked with his arms about nine inches away from his thighs and that makes him look very odd because if somebody's walking around you know with their arms away from their thighs, they look poncy you know [yes], I mean people used to shout after him that he was gay or something [yes], ummm but people certainly interpreted the way he walked as him being gay, which was hard on him because he's very, very macho [yes].

Particularly when he a bit younger he was very macho indeed [yes] and he couldn't bear people thinking he was gay [yes]. ... And when I finally sort of got down to saying why do you walk with your arms away from your sides,

that's partly what makes you, gives you a look that people interpret as gay,... and he said 'I can't bear the feel of my arms against my sides, and the sound of my arms against my sides, so [right], can you hear it?'. [Yes]. That tiny little sound of one cloth against another cloth he couldn't bear, and I said you know you've got to desensitise yourself to that otherwise you will go on looking the way you are, interpreted as gay. And I think he's done it, he seems to have managed to desensitise himself. It's not a problem now is it?

Parents also describe a range of preferences and difficulties in relation to dressing and body care routines which may reflect tactile hypersensitivity. A number of parents describe a preference for being barefoot and all parents with the exception of Parent D describe difficulties in relation to having hair washed or cut. Clearly however, social interaction difficulties or motivation issues may also underlie or contribute to some of the reluctance and distress around hair care:

Parent B: He liked to be barefoot most of the time, he didn't really like wearing shoes.

\*R: Was that a problem, keeping shoes on?

Mum: It was when he was younger, yes, yes, it was.

Parent E: Dad: For a long while he didn't like shoes on.

Mum: He preferred going barefoot to having shoes...mmm he still prefers not to have them on

Parent D: he's always got barefeet in the house. ...Um he didn't like putting his socks on particularly. I mean obviously if we were going out he knew, he'd put his shoes and socks on, but everytime, even now, in the house he always had barefeet.

Parent B: Well that was a problem. Umm he didn't have enough baths and hairwashes because it always was such a problem just to get him to cooperate. And haircuts, well I just didn't take him for haircuts. I tried to cut his hair myself which was really difficult because he'd



never stay still very long and I'd be chasing him round with a pair of scissors to try and get him to stay still long enough to snip his hair, which was really crazy. When he got to special school they had this thing where after they had a swim they all used to have a shower and a hairwash and they had someone come in and cut their hair now and again, and it was fantastic. (Right) You know, it took a great weight off. ... It was probably, at the time I just thought he was being really awkward because he didn't understand the need for it, but I think now it might also have been that he didn't like the feel of someone pulling at his hair and cutting it, probably didn't like that at all. But he couldn't say at the time.

Parent C: Oh yes, yes! I think, I'm sure it was C who screamed for the first six months of his life when he had his hair washed, and this continued, he really didn't like having his hair washed (right) and we couldn't get it cut, and I had someone come to the house.

Parents E: Mum: Yes, dreadful [ Having hair washed]

Dad: On the other hand, a lot of children are like that [yes].

Mum: Yes, but we really had to work on E. Having his hair washed was a big, big problem. We solved it by having a great palaver of putting towels on the draining board - so this must have been pretty young - towels on the draining board and we could, I now don't know how we persuaded him to lie on these towels, but he would lie on these towels - I think somewhere there was a little kernel of reasonableness in him, ha ha ha! Somehow we persuaded him to lie on these towels with his head at the end and then I would wash his hair over the sink [uhum] - as you would in a hairdressers I suppose.

Parents G: DAD: Yes, he was quite happy for us to do it [hair wash] wasn't he?

MUM: He's always been very happy for us to do anything to do with his body if other people attempt to do anything, whether that's the dentist, (DAD: hairdresser!) then there are real problems.

\*R: Has he been able to verbalise what that is?

MUM: That's a touch thing isn't it?

DAD: "It's somebody I don't know touching me." (MUM: Yes) Whether this is still current, I mean, he had to have his hair cut recently and there was an enormous, enormous palaver over it and he laid down all the conditions which had to be fulfilled and... it was sensible in a way from his point of view but it had to be, it couldn't be a hairdresser down here because he had to pass that shop on other occasions and so that person would see him in another context, it had to be a different location, the hairdresser had to be briefed beforehand as to exactly what was going to happen (MUM: and not talk to him) and not to talk to him (MUM: while he was having his hair cut!) - it was all set up, you know behind closed shutters, after hours!

MUM: But the actual haircutting, if it was by somebody else, that was a touch feeling that he didn't, couldn't cope with, but actually our doing things like that is not a problem.

DAD: Yes, he's quite happy for you to do it.

MUM: Yes.

### **Hypo-sensitivity**

All parents note some form of behaviour indicating a degree of unreliability with regard to awareness of, or accurate identification of, internal body sensation and states. The most common phenomenon described is that of general under-reactivity to pain (not however, reported by Parent D) but under-reactivity to temperature, thirst, hunger, satiation, and 'illness symptoms' are also described. This unreliability can pose serious problems for health and well-being. Hypo-sensitivity in relation to 'external' sensation in taste and smell is also described by one parent.

#### *Under-reactivity to pain*

Parent A: Mum: Yes, I don't think he... You know I would have, before I thought he was autistic, I would have said that he was just a



stoical little chap. He didn't make a big fuss [Right] if he hurt himself it was very difficult to know if he had hurt himself, if he was in pain in fact [Right, mmm]. ... Well, there'd be earache. I mean one time he actually had a discharge from the ear before I realised he had earache [oh right]. He must have been in quite a bit of pain [Uhum, uhum]. I can't remember any particular times when he'd injured himself, I just sort of remember feeling and knowing - he didn't make a big fuss when he was hurt [Right].

Parent E: Mum: I think he sometimes had problems knowing where he'd hurt himself [right]. He seemed to find it difficult to localise a pain [right], when I knew where the pain was because I could see it, you know, when he'd grazed his knee or something like that [uhum], I thought sometimes he had difficulty finding it

Parent F: That is, he has an INCREDIBLY high pain threshold. Umm, that's possibly the most striking thing about his sort of sensory perception actually. He umm, when he started getting ear infections, which was when he was a little baby, several times his eardrums burst [oh] and in the end they realised, or I realised and the doctor - we had very good doctors where we were living - that he wasn't complaining until the thing was literally on the point of bursting [right] so we had to have this arrangement whereby if he said his ears hurt I just rang up and they put antibiotics out and I would go and get them. In the most recent, EXTRAORDINARY example, was that he had a very, very nasty sinus operation after Christmas where he had his sinuses re-bored and umm his septum straightened and the spur cut off, and everybody said to him umm 'This is very painful but it will be worth it in the end'. And a friend of mine, an older man who'd had this operation said 'It's absolutely dreadful and you wake up in agony, you've got your nose packed, it's really terrible. Don't leave him because he will be in such agony.' When we went in, the nurses said 'Oh it's all right, we've got morphine for when he comes round.' And I had suspicion that he wouldn't,

because he doesn't feel pain very much [oh right] but I thought well even this is going to get through to him, and they brought him back from theatre and, obviously he was doped up to here, and it was so, the nurses just couldn't make him out at all, and they came and said 'F we've got some morphine here, does it hurt?' And he said 'Ohhh, noo', and they said it must hurt. And I said 'F, you know, you've had, it must hurt, the nurses have got these things', 'Well, it's a bit uncomfortable' [Oh] and it obviously just, and he actually took the packing out of his own nose in the middle of the night [oh no] and the nurses were just astonished. And in the end they kept on and on and on and ummm he took the morphine that they gave him and it just completely crashed him out again. And they gave us all sorts of painkillers, he was going to have two weeks off, and they said we've left some splints in his nose. Well he came home, didn't take any more painkillers, within sort of a couple of days, although he was coming out with me 'cos he was bored. And we went back to have what Chris and I thought were tiny little splints out of his nose which he'd been walking round with for a week, and when a friend of ours took them out, they were this big [oh gosh], they were just huge. I mean Chris and I were sort of going through the floor watching these things and I said to him 'Didn't it hurt having those things up your nose?' 'Nooo'.

*Under-reactivity to temperature*

Parent C: Mum: No, he must feel the cold 'cos he's always putting gloves on, and we'll say 'You don't really need your gloves on now C, it's quite warm.' His hands do get cold but he doesn't seem to feel the heat. ... We have to tell him, we've had to instruct him, and we try to get him, now he's older, to say watch the weather forecast, that'll give you a clue, and sort of different temperature, like if it's 10 you don't need your hat and your gloves on (Right) and if it's over 20 you need to be thinking about a sunhat and..

\*R: Right. So you've helped him with the rules around weather  
Mum: We've got to otherwise he's you know he's no idea.

Parent G: DAD: He doesn't seem to perceive ambient temperature  
(MUM: No) at all coherently in terms of going out in the cold with  
inappropriate clothing on but then obviously you can see, right down  
to him going blue, whatever, but he doesn't seem to perceive that or  
have felt that as an inconvenience and then the opposite also being on  
a sunny day having all your woolly jumpers on (MUM: coat and  
kagoul!) and going all red in the face and again he doesn't seem to feel  
uncomfortable or recognise what he feels as discomfort caused by that.

*Under-reactivity to hunger, thirst, satiation*

Parent A: Mum;... and ummm he'll just go on eating, you know, old  
ladies are always delighted in having him to tea [right] and you know  
our neighbour, famously the first time we went round, he ate ten  
mince pies. You know [right!] he'll not sort of, nothing will sort of  
teach him you know that I'm feeling full up and sick [yes] and he won't  
stop eating 'cos he feels sick. So we've had to teach him the really hard  
way to stop, it's always been very difficult and I've always felt it's  
because he doesn't seem to know when he feels ill.

Parent G: MUM: This is another one, yes. [[registering hunger and  
thirst]

DAD: Oh, yes, oh I'd forgotten about that, well yes, totally. Yes.  
Always, both ways, every way you want to look at it (MUM: ha, ha!).  
Not eating or drinking for long periods of time (MUM: oh yes,  
dangerously at times) and then feeling peculiar sensations but not  
knowing what they were.

MUM: "I've got these pains here, why have I got these pains?" "Well,  
have you had anything to drink today?" "I haven't had anything to  
drink for days." and it was this sort of...

DAD: And then eating vast quantities as well if it was available. I mean he's much better at this sort of thing, he's much more self-regulated although I mean there are still elements of this (MUM: yes).

However, this under-reactivity may exist alongside apparently 'normal' responses or indeed hyper-reactivity in other situations. Within a general context of under-reactivity a number of parents also provide examples of normal or hyper-reactivity at other times to certain types of pain or illness;

Parent F: However, if a needle is involved [right], he is completely the other way, he's absolutely terrified of needles. So we had that experience with everybody just astonished that this child apparently felt no pain with this terrible operation. He then split his leg open, which he's done twice this year, and umm had to be stitched, and you have never SEEN such a fuss and he insisted, even though he was lying on his tummy, and turning round and watching the needle go in [right] every time, and he made the most colossal fuss, and the sister who did it said afterwards 'I've just been delivering twins here' and it was just somehow the needle somehow switched, you know if he has to have a blood test he goes green and grey [right] but generally, I mean when he was little he would fall into, I remember him falling into a whole load of stinging nettles, coming up in big lumps and not crying [right], he just didn't feel pain and still, he still is, you know he gashed his leg right open here, he split his heel very recently and he was just holding it together, you know, not sort of, just doesn't feel pain, an incredibly high pain threshold [right, right].

Parents E: Mum: Well he must have been in some way [insensitive to pain].

Dad: Yes, very stoical about it.

Mum: Very stoical, and yet there were places he couldn't bear to be touched so that when he first went to the dentist. I mean the dentist was a major, major problem. In fact he didn't go to the dentist [uhum] for some years because he couldn't bear the thought of anybody touching his mouth [uhum]. And when he

finally went, now I thought that he had to have Valium before the dentist - I still think that's true - but he denies that, so I don't know [oh right]. He says that in the end he didn't have Valium.

Parent C:... except that he doesn't seem to feel pain.... You know, he can drop something on his foot or cut his finger and - he did hurt when he shut his finger in the car door, but apart from that.. Yes, he can put his hand in boiling hot water and not realise it.

Parent E: Mum: He preferred going barefoot to having shoes, and he didn't have a sense of cold on the whole, except that I can remember a terrible picnic when he got cold and the whole thing was ruined by him being cold [right] but on the whole we were constantly saying 'put something on' rather than, and still do, he still has no sense of cold, I think [right].

A number of potential contributory factors to these phenomena can be identified from parent accounts. These include self-absorption suggestive of an over-narrow attentional focus, poor memory or recall, impaired social communication and with regard to satiation, compulsiveness around eating and drinking. However, it is unclear if these factors alone can account for the sometimes dramatic examples of dysregulation described.

Parents B and C seems to suggest that 'being in his own world' is a causal factor in under-reactivity to pain

Parent B: Yea, because he used to run along the street to school and he often used, because he was just completely in his own world, he'd just fall flat on his face or bump into a lamp-post, but he just didn't seem to even notice, he'd just pick himself up and carry on.

Parent C: No, because he never seemed to notice what we were doing. Poor little soul had a broken toenail once when he was a baby and I hadn't realised - and because he never, I mean he was quite young, and

I realised that it was bleeding once again, and it hadn't registered or anything, until I took his sock off!

Parent B suggests that an additional factor may have been B's lack of interest in communicating:

Parent B: No, no he didn't think to tell you if he'd had an accident.

Parents G suggest that poor memory or an inability to recall previous experiences of illness contribute to G's inability to accurately label symptoms of common illness:

Parent G: MUM: He does, I mean there's a whole thing that we've had of colds because whenever he's had a cold as a child he has started as if he's dying because he hasn't been able to recognise the symptoms even though a few months ago he'd gone through it. So each time it's like a new experience and that has gone on until fairly recently, and it's only now, perhaps in the last year or so? (DAD: about) that he's been able to say "Yes, I think I know what this is" and that will apply to all symptoms really I suppose, feelings he just hasn't been able to remember.

Parent A suggest that an element of compulsiveness characterises A's eating and drinking which could over-ride feelings of satiation. Parents G describe a similar process which they describe as an 'lack of control'

Parent A: Mum: ... I was talking about the time when he nearly choked at New Year's Eve. He must have been feeling quite ill there but this way he sort of eats compulsively regardless of what he feels like. He isn't ill very much anyway but even when he is, I can't ever remember him saying 'I don't feel very well, I have a headache or I have a stomach-ache or I have anything'. You just sort of guess and ask him. [Dad: Mmm]



Parent G: MUM: He eats - again it's going back to not knowing when to stop - he can eat many apples at a sitting.

DAD: We can't have a bowl of fruit out in the house, we've been through all this with him, 'cos we go shopping and put two pounds of apples in, one hour later they're all gone (Right) even the pips 'cos he eats an apple in total.

MUM: He does actually leave the stalk (DAD: except the stalk, yes) at the moment.

DAD: A favourable ad lib, he won't have difficulty judging, the end is when there'll be no more to see. (OK)

MUM: He doesn't seem able to be able to control himself whereas the other children can. if there's a tub of ice-cream in the freezer, although the others might want to have some, they wouldn't eat it in the same way as he would just consume it until it's gone! And even though we say "You must not have that because we're saving it for such and such a meal"...

DAD: The impulse will be very strong (MUM: yes) and he'll say "I had to" (MUM: oh yes) "there was no choice available to me in this situation". "You can't criticise me for choosing wrongly, choice did not come into it, I had to."!!!

However, Parent F later suggests that F's distress at needles arose from a specific incident around the age of six or seven involving the sight of blood during a blood test:

\*R: When did this thing about needles begin, I mean was he always even as a baby sensitive to this?

Parent F: No, he, I think it was after we moved here. No because when, not it wasn't because when he had his injections he never cried as a baby [uhum] and again they said 'Oh this baby doesn't cry' and even when he was five and they had the pre-school one he didn't cry and he had quite a bad reaction, his arm came up so much we couldn't get the shirt on him, and he didn't cry but there was, he went to have an operation, I can't remember where it was, whether it was here or in Leicestershire, and umm he had to have



a blood test, and he'd never had a blood test before, and ohh, it was the story of my life when he was younger, trying to explain to people that he wasn't being silly, he wasn't being naughty, he was genuinely frightened [yes], I mean you know F's fear was what sort of made F be as he was, and these people didn't listen and they used to blood test very insensitively, not for your average person but as far as F was concerned it was extremely insensitive the way they did it. He was grey, he was about seven I think, six or seven, umm and of course seeing his blood I think coming out [uhum] absolutely threw him. Umm and since then needles are just a complete no-go area. [OK] But before that he hadn't worried.

These difficulties with internal body states are described as being present very early in childhood but there is considerable variation in the extent to which they have now been reliably overcome. Parent B indicates that lack of reliable awareness of pain is no longer a problem for B. Parents E suggests that pain awareness is now normal, and, that well into adulthood his awareness of cold is gradually becoming more 'normal'. Despite some improvement with age, Parents G suggest continuing difficulties in awareness of pain, temperature, hunger and thirst. Parents C indicates a continuing problem with regard to lack of reliable pain perception for C. Parents A describe continuing difficulties with regard to awareness of pain, illness and satiation.

Parent F: That hasn't changed. He walked around with a broken foot for seven weeks last year, umm, and umm he did it, he came home from basketball with a very swollen foot. And umm, I haven't learnt you see, I really haven't learnt with F, and I thought I can't really take him to the hospital, waiting in Outpatients, I'll wait and see what happens. I borrowed a walking stick for him, and the next day he would walk on it so I thought Oh it's fine, and he went to London a few days later for a week with school and then he came back, it was this time last year, and he jumped into, by that time it seemed perfectly all right, he jumped into the swimming pool and said 'Oh, hurt my foot' and he carried on for another three weeks and then one Sunday

afternoon I thought he was just being awkward, he said his foot hurt and, I wasn't going to do anything about it, and Chris took him to the hospital and it was fractured [oh dear] and you know you wouldn't have thought to look at him, he'd just been walking around on it. And I then broke my foot and it was one of the most painful things I've ever done [oh] and he's, he is extraordinary.

Parents E: Mum: I think he's improving actually - well improving, he's getting more normal - in terms of beginning to feel the cold, umm he's now quite pleased to wear a sweater, if he likes it [right], and that's partly about appreciation generally.

Dad: He'll come home and go out for the evening in a T-shirt with nothing else in the winter [right] [Mmm] and you worry how on earth he can stand that cold [uhum] and what will he look like after midnight wandering around in a T-shirt [mm].

Mum: Yes.

Parent A suggests that knowing about internal sensations such as illness, feeling full are still a problem for A

Parent A: Mum: No, he never complained of anything really. I mean it's been very difficult, it's always been difficult to know when he's ill but he doesn't actually get ill very much anyway [right] but on the odd occasions he's got up clearly looking washed out and sick and ill, he'd still try and get up and carry on with the normal routine and we'd have to say to him 'You don't look right, what do you feel like, don't you think you ought to..'. He doesn't seem to be that in touch with sort of what he's feeling like ....

Parent C: Yes, he still doesn't feel pain.

Parent B: Yes. I think he reacts normally if he stubs his toe or something, gives a shriek, it's quite normal now I think.

Only one parent identified 'general' hypo-sensitivity within one or more modalities.

Parent C suggests that her son is generally under-reactive to smell and taste:

Parent C I don't think, even now, he doesn't seem to taste things, you know, he'd have something that was completely unusual and you'd say 'how's that' and he'd say 'it's fine'. (OK) Just to me, it's, you tend to have something and you think 'Uuugh' but I can't think I've ever seen him have an expression that.... that 'Oooh, this is wonderful, I'm going to have some more of this'... He just seems to treat everything with the same sort of everything, yep, OK, start eating this.

Parent C: And he doesn't smell things. You know the other one's got a very strong sense of smell and he'll come in and say 'Mm, Mm, something's...' and he'll identify what's cooking or he'll say 'Oh, that's a horrible smell', you know, it's really awful, and C just doesn't seem to do it. You'll say 'Can you smell that?' and he'll say 'No' you know... I mean he puts aftershave on and he puts gallons of it on, and we all go 'Uhuh, uhuh' and he doesn't seem to notice... Yes, and it's on, it's on his face, it's right near his nose and he doesn't seem to notice the smell at all.

## **Appendix 12**

This appendix relates to Chapter 6, Study 4. It contains a more detailed account, with illustrative verbatim data, of the analysis of first-hand accounts than is presented in Chapter 6.

### Analysis of first-hand accounts

In presenting the analysis of the public accounts of these individuals with autism each of the core categories outlined in Study 2 will be considered in turn.

#### ***Perseverative bias***

This concept subsumes a range of experiences and behaviours which have in common a heightened disposition to repetition and sameness. The analysis of first-hand accounts provided support for this concept of an orientation or predisposition to repetition and sameness. This is represented in the accounts in a number of ways: in descriptions of the intrinsic appeal of repetition and sameness in activity and sensory events; in descriptions of perseverative thought, and, in one account, the experience of sensory echoing; in descriptions of repetitive and stereotypic behaviour; and in descriptions of a preference for the familiar and a corresponding dislike of the unfamiliar.

All authors describe repetitive stimuli and activity as appealing. The authors identify repetition and sameness as pleasurable, or, as having a positive impact for a number of reasons which may vary at different times. These include descriptions of repetitive stimuli as intrinsically pleasurable or appealing, as providing a sense of coherency, control or comfort in the context of a world which is perceived as constantly changing and unpredictable, as calming, as facilitating a process of retreat into an inner world, or as helpful in shutting out confusion or painful stimuli.

#### *intrinsically pleasurable*

I loved repetition. Everytime I turned on a light I knew what would happen. When I flipped the switch, the light went on. It gave me a wonderful feeling of security because it was exactly the same each time. Sometimes there were two switches on a plate, and I liked those even better; I really liked wondering which light would go on from

which switch. Even when I knew, it was thrilling to do it over and over. It was always the same. (Barron & Barron, 1992, P. 20)

Up to the age of seven or eight, I spent hours enjoying running my fingers over and scratching on the edge of my pillow case which had embroidery around it. I still do this now with different surfaces, especially if it feels good and makes a small sound ... I liked opening and closing the doors of some of my toy cars, and in particular watching the wheels as I turned them round. I used to put them one behind the other in a long line so that it looked like a long traffic jam, although this was not the intention: I used to put lego bricks into long lines as well (Jolliffe, Landsdown & Robinson, 1992, p.12-13).

*control, comfort and coherency*

The constant change of most things never seemed to give me any chance to prepare myself for them. Because of this I found pleasure and comfort in doing the same things over and over again (Williams, 1992, p. 39).

Spinning was another favorite activity. I'd sit on the floor and twirl around. The room spun with me. This self-stimulatory behavior made me feel powerful, in control of things. After all, I could make a whole room turn around. Sometimes I made the world spin by twisting the swing in our backyard so that the chains would wind up. Then I'd sit there as the swing unwound, watching the sky and earth whirl. I realize that non-autistic children enjoy twirling around in a swing, too. The difference is the autistic child is obsessed with the act of spinning. (Grandin & Scariano, 1986, p.22)

*calming/ retreat/shutting out*

I screamed and screamed and Kerstin sat with me in bed half the night, cutting traffic lights out of cardboard, the only way of calming me down. She cut-green, red and yellow, stop and go-clear signals with a

clear message. I liked traffic lights and they had a calming effect.  
(Gerland, 1997, p. 45)

So it is with autistic children. They have to make a choice of either self-stimulating like spinning, mutilating themselves, or escape into their inner world to screen out side stimuli. Otherwise, they become overwhelmed with many simultaneous stimuli and react with temper tantrums, screaming, or other unacceptable behavior.... The autistic child self-stimulates to calm himself (Grandin & Scariano, 1986, pp. 24-25)

I learned eventually to lose myself in anything I desired - the patterns on the wallpaper or the carpet, the sound of something over and over again, the repetitive hollow sound I'd get from tapping my chin. Even people became no problem.(Williams, 1992, p.3)

These descriptions convey a quality of intense absorption in repetitive stimuli or activities. One author explicitly describes the cumulatively 'entrancing' impact of repetitive stimuli and activity which made interruption difficult.

One of my favorite things was chains; I loved the texture of chains. Each link looked the same and even felt the same as all the others. Because the chains on our garage were too high for me to reach, they were very mysterious to me—I wanted so much to touch them, but I had to use a stick instead. Since I couldn't reach them with my hands, I made them swing. I really loved the repetition of the swinging movement—I wanted to see the chains from all different heights and angles. The more I saw them swing, the more entranced I became, and the more I wanted to do nothing but watch them. It was what I loved. It was my routine. My mother kept trying to interrupt me, but that never stopped me. (Barron & Barron, 1992, p. 31-32)

Within the authors accounts there was also evidence of perseverative thought and from one author for a perseverative experience of sound. Barron & Barron's (1992) account suggests that this internal echoing or repetition of



thought was also pleasureable and could serve a similar 'shutting out' function as other repetitive activities:

I loved the information I could obtain on radio and TV call letters—the letters themselves and the cities where they were located. It was easy to find the information since the stations were listed in National Geographic magazine. I knew it was knowledge that few other people had, and that made me feel excited and powerful— so much so that I kept a list of the call letters in my head. On any given day one station's letters would stick in my mind, repeating themselves over and over. I'd use these repeating letters to shut out the people around me and all the things going on that I didn't like. The sound of the letters was strong and vivid, blotting out all my insecurities. I did this for many years and it always made me feel powerful. I was the only one in the entire school who had this information, and as long as the letters spoke in my head, I was no longer inferior (Barron & Barron, 1992, p.120).

... they may not want to go to a certain place because the noise echoes in their ears. You, on the other hand, do not realize this because they can't tell you (McKean, 1994, p.51)

A strong theme of repetitive behaviour, of repetitive motor movements, repetitive activity with objects and of 'thought fixations' is evident in the accounts of these authors. In addition to the import and functions already outlined, analysis of authors' accounts highlights a number of other facets to this behaviour. There is evidence that repetitive behaviour may occur 'automatically' without awareness. Two authors speculate that the function of this 'automatic' repetitive behaviour is to regulating the level of arousal in the nervous system and in the case of Gerland (1997) that it facilitated transition from one state of consciousness to another i.e. from wakefulness to sleep.

I made sounds in those pre-school years-sniffing and grunting noises- whenever I was doing things. If I was drawing, I might sniff at regular intervals; when I was in bed I would make grunting noises before

falling asleep. The sounds most often came when I felt all was calm and quiet. I never noticed them myself, but they often disturbed those around me. Other children, Kerstin's friends, found them annoying, and at first I didn't understand why they kept telling me to be quiet. I hadn't said anything, had I? The sniffing and snoring noises were as unconscious an accompaniment to what I was doing as was the beat of my heart. I simply didn't hear them. As I grew older, I realised I was making noises the moment someone told me to stop, and I'd make an effort to stop, but after a while I unconsciously drifted back into making them. They were only there because they needed to be there, perhaps helping me to keep going in the same way as the engine noise in the car made my nervous system wake up and function better. (Gerland, 1997, p.30-31)

But regardless of how I was lying in bed, there was always one way of getting to sleep, and that was to toss my head to and fro on the pillow, from side to side, very quickly. This was the only way to fall asleep. In the daytime, I could just shut out the world, sink into myself and switch off wakefulness without falling asleep. So in order to be able to get past that place in which wakefulness was switched off but sleep not yet switched on, I had to find another method of falling asleep. My method worked well, although occasionally I had to keep tossing my head to and fro quite violently for a long time (Gerland, 1997, p.105).

However, there is also evidence that repetitive behaviour may serve other functions. There is evidence that repetitive behaviour may occur because of boredom, or in the case of repetitive questioning because it provides a predictable and controllable structure for interaction or allows the questioner to 'show off' knowledge.

I had a driving need to ask questions about the states because I felt I could not talk the way "normal" people talked, nor could I take part in their conversations, since I didn't understand them. Everyone else talked effortlessly, their conversations flowing as smoothly as a creek, and I felt very inferior, shut out, less important. I had to compensate

for what was lacking, and what better way than to show people that I knew all fifty states, their positions on the map, the shapes of each one? I needed to show everybody how smart I really was, and by asking the questions, I was doing just that. I never asked, "What states have you been to?" but rather, "Have you been to Montana?" so that I could show them I knew all the states. (Barron & Barron, 1992, p.105-106)

Another thing I liked about the states conversation was its structure. I tried to talk to whomever it was for as long as they'd let me, and I never once got tired of the conversation. I would ask about all fifty states if no one stopped me. This made me know I was in control of the conversation. Even if I couldn't talk the way everyone else did, I could dominate and control what was said; after all, I did have fifty states to choose from. I wanted to get attention for something other than the things I did that were wrong! (Barron & Barron, 1992, p. 106-107)

An element of compulsion is also identified in two of the accounts as underlying specific aspects of repetitive behaviour. Barron & Barron (1992) describes a compulsive need to 'check' for sameness underlying some of his repetitive behaviour. This feature was described in relation to some of his earliest memories and persisted despite clear 'cognitive' understanding of the constancy of physical structures and objects:

I remember lying on the floor picking at the carpet with my fingers. It's one of the first things I do remember. The feel of something that was not perfectly smooth was wrong to me—I picked at anything that did not have a solid surface. One rug in our house had many small ridges; by scratching them I could tell that all of the rug was the same, even if it looked different. I had to keep picking at it to be sure that the whole rug was the same, all of it. It must not change! (Barron & Barron, 1992, p.15)

Mom would say, "Sean, you know that hole goes to the basement, " with the hope of quelling my interest, but that was not what I wanted.

I had to see for myself, over and over. I needed to test the depth between the hole and the basement floor, although I was fully aware that I would not actually be able to touch the floor, because it was too far away. I used my finger as a point of reference. I had to keep seeing for myself that the hole was at least as deep as my finger was long. (Barron & Barron, 1992, p.78)

Gerland (1997) on the other hand suggests that in her case compulsion in repetitive touching arose as a way of managing a chronic and unpleasant sensory problem:

I began to develop compulsive rituals. By running the tips of my fingers or pressing the palm of my hand against something, the shuddering might first increase but then reach a point where I no longer felt it so acutely. As if I could raise its frequency so that it lay beyond what I could perceive. Curved things were what I wanted to touch. I grasped every door- handle I passed. I put the tip of my forefinger just where the handle curved. This felt good. I followed the banister rail with my hand all the way to the middle where it curved, then stopped and rubbed my palm back and forth on the curve. I did that every time I went up or down the stairs, and always at the same spot. I had to do it every time to calm my spine. (Gerland, 1997, p.57-58)

With age a number of authors indicate that the appeal of repetition and sameness was expressed in a more abstract form, in narrow repetitive interests or 'fixations'. Grandin & Scariano(1986) suggest that these fixations played a similar arousal regulating function as earlier repetitive motor movements:

I had an intense interest in dead-end streets. The things I liked to do, in general, were those that offered some variation but were still repetitious. So dead-end streets were perfect. I knew the different ways that such streets could look— two neighboring streets could both be dead-ends but look and feel totally unlike each other. Yet they both

ended, and in that way they were the same.... So dead-end streets fit my rule— a little variation with a lot of repetition. I loved being in the car and seeing a dead-end sign. I would look up that street for as long as I could, trying to see all the way to the end. Sometimes I could actually see where the street died, but most of the time I could not. When I couldn't, I desperately wanted to travel up it— that was the only way my curiosity could be satisfied. Questions raced through my mind: Does that street go into the woods before it ends? Does it end in a circle? Does it turn into a driveway and stop? These questions would get into my head and stay there, going around and around. (Barron & Barron, 1992, p.89-90)

As a rule therapists object to catering to fixations. But many fixations in the autistic type children have to do with a need for reducing arousal in an overactive nervous system. By concentrating on the fixation they block out other stimulation which they cannot handle. ...My fixations reduced arousal and calmed me.(Grandin & Scariano, 1986, p. 109)

A number of authors described a very strong preference for the familiar in their lives and a corresponding dislike of change and the unfamiliar. Familiarity is described as comforting and safe. Gerland (1997) suggests that a need for predictability, to be prepared in order to cope, was the basis for her dislike of 'surprises'. Similarly Weekes (1995) suggests that familiarity and 'knowing what's coming' next facilitates a sense of coherence and order:

There were several reasons why I wanted to keep my worn and much-too-small old shoes. It was because everything else hurt my feet, but also because in general I didn't like new things. I just liked things that were familiar, things I was used to, so they couldn't cause me any surprises. There were battles over what I was to wear on my feet. I usually won. My dislike of surprises applied to all areas of life. I didn't want to be surprised, not ever. If I was to have any chance of coping with situations, I had to be prepared for them. I might like to be given presents, but I found it hard work not knowing what they contained.

As jewelry was so terrifying to touch, I preferred to be prepared for the contents of all presents-just in case. My absolutely favourite present was the one I had every Christmas and which I could quite easily recognise from the outside. I could recognise that parcel under the Christmas tree from a long way away. You couldn't mistake the shape. It contained a large tin of pineapple, which was one of my fixations - so every year I was given a whole tin which was mine and mine alone. (Gerland, 1997, p.137)

You know it's a funny thing with autistic people they like sameness - autistic children all through the various age groups all like sameness - the more thing that can be the same the better simply because they know what's coming next and um things are more coherent for example if as a child I'd like to wake up and know what was going to happen on that day as far as possible and that was very far y'know otherwise it'd be a tantrum for them. I'd always had problems getting a sort of coherency out of the world unless I could be in somewhere I was very familiar like in my room, my space. (Weekes, 1995).

Change and the unfamiliar are described as stressful and as causing fear and anxiety:

I tried to take in these new circumstances. I couldn't grasp why my sister could seem so unmoved. How could she go out into that unknown garden and play with unknown children? I couldn't understand, when my terror was so great, how she could look as if this was like any other day. Bewilderment buzzed inside my head. (Gerland, 1997, p.45)

Just as I got used to them, I drew back the covers one day to find my father's girlfriend had changed them[sheets]. Trying to control the tension in my voice, I asked, 'Have you washed the sheets?' 'Yes,' replied my father's girlfriend authoritatively. 'I don't like to wash them,' I informed her. 'Well around here you do,' she said crisply and invited no response. I went to the room and sat on the floor,



screaming silently in my head. No words came out but I felt deafened. (Williams, 1994, p.41)

It is clear that with age a number of authors gained insight into the limiting effect of this tendency to get caught up in perseverative thought and activity and made efforts to overcome or limit its effect on their lives

Since playing cards were a major temptation to me, I threw away all my decks of cards and told my mother what I was doing and why. Dead-end streets and bus numbers still went round and round in my head, and I pushed them out. I made myself think other thoughts instead. (Barron & Barron, 1992, p.232)

I still have a bent- I like that word-for curved things but it is no longer a fixation. It comes out mostly in things like finding I want to make a detour in order to take a road that bends instead of a straight one, or feeling a desire to touch something that is beautifully curved. It is good that I can choose to allow myself a detour, to enjoy that curve but that I can choose not to if I think I haven't the time. And I know when it's all right to touch whatever arouses my desire to touch and when not, and I don't find it difficult not to. (Gerland, 1997, p.249)

In comparing the individual accounts there is evidence of variability in the extent to which this orientation to repetition and sameness is described as a central aspect of experience and behaviour. Barron & Barron (1992) for example describes this orientation as a very significant and pervasive aspect of his childhood experience. As an adult he describes himself as continuing to actively avoid slipping back into earlier patterns. McKean (1994) on the other hand describes a much less dominant orientation. This variability supports the idea of individuals placed at different points along a continuum.

### ***Faulty Modulation***

This category relates to descriptions of faulty 'modulation' in the perception of both the external and internal sensory environment and other abnormal or



irregular experiences in bodily awareness. It subsumes the concept of hypersensitivity developed in Study 2 and locates this phenomenon within a wider category of disrupted modulation which includes hypo-sensitivity and other anomalous experiences of body state. In the analysis of interview accounts in Study 2, hypo-sensitivity was considered to result from an over-narrowed attention beam as the most parsimonious explanation for this failure to become aware of both internal and external sources of body sensation. However, in the analysis of first-hand accounts hypo-sensitivity emerged as particular to various aspects of body awareness. Evidence linking it to situations of over-narrow attention only was not found. Thus a wider concept of faulty modulation was considered necessary to represent the range of over- and under- reactivity reported in these accounts. There is individual variability in the range and extent of the experiences reported in this category.

### **Hypersensitivity**

Analysis of the authors accounts supported the concept of hypersensitivity. Hypersensitivity is reported across the modalities sound, vision, touch and smell. Across individual authors, hypersensitivity in sound and touch are the most common hypersensitivities described. The term is used to include hyperacute or intensified experience of sensory events and a more specific problematic sensitivity to particular sensory events. These aspects may co-exist within the same modality or may be reported in different modalities.

### *Sound*

All authors with the exception of Barron & Barron (1992) refer to some form of hyper-sensitivity to sound. An amplified volume experience of sound, hyperacuity for specific sounds or painful reactivity to a broad range of sounds are described. These experiences are described as resulting in a range of negative social, psychological and behavioural consequences and as increasing a sense of isolation and misunderstanding:

*amplified volume*

The noise of the sewing-machines went right into me, too, vrrr, vrrr, clackety-clackety-clack, vrrr, vrrr. The sound didn't make me lose my foothold as other sounds did, but I simply couldn't shut it out. It was louder than I could have imagined and it exhausted me, as if it were a battle between me and the noise, in which I tried to hold out my arms and push it away from me with the palms of my hands. (Gerland, 1997, p.177)

*hyperacuity for specific sounds*

Whenever they spoke to me, or called to me, I would be sitting on the floor. But I didn't hear them. I was absorbed in what I was doing and heard nothing, cutting up tiny bits of paper, totally concentrating on what I was doing. But whispers came rushing at me from a long way off, always straight into my head, easily passing through all the passages in my ears, sliding directly up into my mind and rousing it. I didn't have to be on guard for whispers. I didn't have to wait to let them in. Whispers had their own key. So if people whispered when I was cutting out my little bits of paper, I looked up. (Gerland, 1997, p. 32)

*problematic sensitivity*

Certain sounds frightened me- dogs barking, mopeds, tractors and cars, engines of various kinds. They would explode inside me and make me lose all sense of the way my body related to my surroundings. It was like being flung out into space. Straight out into space-whoosh- quite without warning. Sometimes I screamed and covered my ears, and my mother was embarrassed when I behaved oddly. (Gerland, 1997, p.28)

Analysis indicates considerable variability between authors in the types of sound to which they were hypersensitive. This variability is highlighted by Weekes (1995) who clearly is aware of others' accounts of this phenomenon and who sees sound sensitivity as characterising the sensory experience of many children with autism:

Often autistic children will be severely distressed by some sounds and they mightn't be sounds you'd expect they needn't be loud sounds they can be so soft you can hardly hear them. Georgie Stehli in America after her sound sensitivity became much better was able to say to her mother when they passed a certain building on the street and she went bananas um it was because of a very soft shh shh in the outlet pipe in the air conditioning in the building. She couldn't stand the rain. Other children it's high pitched sounds and might be loud sounds some kids are just are just thrown into absolute terror and agony by a motor mower starting up or a motor bike um by the washing machine, vacuum cleaner, you know children's voices. In a group of autistic children you'll usually find when some sound or other occurs some who'll be writhing around on the floor with their hands over their ears screaming and kicking.

### *Vision*

Two authors, MacKean (1994) and Williams(1994) describe hypersensitivity to certain visual events which suggests an experience of heightened intensity of brightness or colour and sensitivity to pulsating light. Terese Jolliffe, Landsdown & (1992) also describes dislike of very bright lights the basis of which was not articulated- this may reflect a similar experience. In addition Williams (1992) describes visual hyperacuity which allowed her to perceive minute detail in the visual environment:

My vision has problems, too. The color yellow is blinding. Looking at anything yellow is like looking directly into the sun, even if it is nowhere near as bright . (McKean, 1994, p.66)

The kitchen had fluorescent lights and yellow walls, one of the worst combinations ever. Even from the doorway I could see light bouncing off everything. In my tense state everything climbed to hyper, vision included. There were no whole objects in that room, just shiny edges and things that jumped with the bouncing of light. The fluorescent

light bounced off the yellow walls like sunshine on water. Dr. Marek wanted me to go in there and be blind. Forget it! Why didn't it bother him? How did these people manage to grasp everything in such a room enough to actually use it as a kitchen? (Williams, 1994, p.92)

Other than the wisps, my bed was surrounded and totally encased by tiny spots which I called stars, like some kind of mystical glass coffin. I have since learned that they are actually air particles yet my vision was so hypersensitive that they often became a hypnotic foreground with the rest of 'the world' facing away (Williams, 1992, p. 9)

### *Touch*

All authors with the exception of Weekes (1995) described some form of hypersensitivity to tactile sensation. This included sensitivity to the texture of food, to materials of fabrics, to certain types of tactile sensation and to hyper-sensitivity in particular areas of the body such as mouth, feet, hair, hands, neck and back.

### *texture of food*

I was supersensitive to the texture of food, and I had to touch everything with my fingers to see how it felt before I could put it in my mouth. I really hated it when food had things mixed with it, like noodles with vegetables or bread with fillings to make sandwiches. I could never, never put any of it into my mouth. I knew if I did I would get violently sick. (Barron & Barron, 1992, p.96)

### *Specific types of sensation*

My feeling was special in other areas as well, apart from that of pain. I could never take a shower, because I couldn't stand drops of water on my skin. They hurt. They had sharp little points that stabbed me. All forms of washing had to happen in the bath. It was necessary to have as much water around me and all over my body as possible for it to be bearable. (Gerland, 1997, p. 101)

To be just lightly touched appeared to make my nervous system whimper, as if the nerve ends were curling up. If anyone hit on the terrible idea of tickling me, I died. It was so way beyond unbearable unbearableness that I simply died-or that's what it felt like. Now and again, it did happen that when I fell into the hands of other children I was tickled. The insane panic I showed seemed to frighten them, but it also seemed to spur them on. Kerstin, too, knew how to make use of my terror, of course. If she thought I was being a nuisance and wanted to be rid of me, she only had to hold out a hand and tickle the air a little for me to flee in panic. (Gerland, 1997, p. 39)

*Specific materials or fabrics*

At the age of ten I scored a 9 out of a possible 15 on the Ayres checklist for tactile defensiveness. Tactile defensiveness behavior and hypersensitivity are similar. Wool clothing, for instance, is still intolerable for me to wear. I like the pressure of turtle neck shirts. I dislike nightgowns because the feeling of my legs touching each other is unpleasant. (Grandin & Scariano, 1986, p. 32)

There were other things I had to do every day that made me quite uncomfortable as well. One of these was taking a bath. I felt acutely uncomfortable sitting upright in the bathtub, so I didn't enjoy taking a bath in the least. I absolutely hated the way my bottom felt against the tub, and I couldn't make myself think about something else so I wouldn't feel it. When I tried to sit normally it felt "squishy," and I was extremely sensitive to this feeling. I couldn't shake it off. It was the same feeling I used to have when I couldn't stand to touch our rugs with my bare feet. To make it more bearable, I shifted most of my weight onto one side so that only a part of me came into contact with the bathtub. When they insisted I "sit right," it only compounded the problem. I had no choice—I had to sit in an unnatural way, so baths were a trying experience. Also it made me feel that there was something wrong with me because I had to sit that way. (Barron & Barron, 1992, p. 96-97)

*specific body areas*

My teeth were very sensitive, and inside my mouth the consistency of some foods could be unpleasant, giving me a horrible feeling all over. With unknown food, you never knew what might happen. So if sometimes it was boring eating only skinless sausages and chocolate pudding, it was definitely worth it. (Gerland, 1997, p.14)

When I was a little older, I felt terrible walking around the house in my bare feet. It felt strange and awful to stand up and be still when I had no shoes on. My feet were extremely sensitive. So, when I had to be barefoot, I tucked my toes underneath so I could pick at the carpet with them. (Barron & Barron, 1992, p.15)

*Smell*

Hypersensitivity to smell is described by two authors. Grandin & Scariano(1986) describes a general over-reactivity to smell as characteristic of her childhood. In contrast Gerland (1997) describes a short-lived and restricted sensitivity to the 'after' smell of people on furniture:

I remember she wore strong perfume that made me sick to my stomach every time she got close to me (Grandin & Scariano, 1986, p.29).

I actually thought it smelt peculiar for a long time after someone had got up off a chair, and I didn't want to sit down until the smell had gone. But there was no point in telling them that, because they would just go over and sniff and say with absolute certainty that it didn't smell of anything. So I preferred to stand up. This period when I sometimes stood at the dining-table because someone had recently sat on my chair didn't last all that long, perhaps six months. Then I no longer smelt any particular smells from chairs, and never thought about whether anyone had sat there before me. (Gerland, 1997, p.60)



As is evident from the quotes above, hypersensitivities are described as resulting in a range of negative behavioural, psychological, and social consequences and as leading to a range of odd or unusual behaviours. The experiences themselves are described variously as unpleasant, distressing, painful, unbearable or overwhelming. They are described as giving rise to a range of distressed reactions which include crying, screaming, 'tantrums' and reactive aggression towards others. They are described in a number of accounts as increasing a sense of isolation and of being misunderstood: The authors describe a range of responses and strategies for dealing with their experiences. Attempts to deal with sound sensitivity include physical strategies to block out unpleasant sound and escape or avoidance of situations associated with the experience. In adulthood one author participated in a direct treatment programme, Auditory Integration Training (AIT), which claims to desensitise hearing to painful events.

If the noise was too loud, too variable, or too high-pitched I could stuff my ears with cotton wool or earplugs.(Williams, 1994, p.73)

Before I had started woodwork, the sounds that had disturbed me at school had been the mumbling, scraping and shouting kind, the kind I heard every single component of and could not shut out, as they settled like a thick carpet on my mind. But now these machines came into my life, and with their din pulled the world from under my feet. I would press my hands to my ears when they started up, but nearly always too late. It hurt inside me, and I kept on and on losing all sense of direction and of myself. When the teacher tried to get me to use the saw to learn how to work it, I backed away and ran out into the playground-an entirely healthy instinct, one of self-preservation. Who would voluntarily stand by a band-saw, with hands near the blade, and lose the feeling of where their body was? But in the eyes of everyone around, there was no such logic. Now I was being troublesome again, for no reason at all. But I felt I really wouldn't survive those noises once a week. I felt it so strongly that I managed to be ill every Wednesday when we were to have woodwork. If



necessary, panic would bring on a temperature, and I had to stay at home. Eventually it became all too obvious that I was ill only on Wednesdays, so then I took to a less sophisticated method. I quite simply refused to go to woodwork. I was an immovable rock of intransigence. This led to discussions between my mother, the school and the woodwork master about, as they thought, my fear of using machinery. No one could imagine that it was the actual noise, whether it was me or anyone else who was operating the machine, that so tormented me. Would I consider going if I didn't have to use the saw? (Gerland, 1997, p. 115)

McKean (1994) relates his experience of reduction (albeit temporary) in hypersensitivity as a result of AIT treatment:

When I left Cincinnati to return to Columbus, my hearing had definitely changed for the better. I noticed I could turn the stereo in my car up a little louder than before. (And I did, when "Rock & Roll Heaven" came onto the oldies station.) The sirens that go by my apartment on the OSU campus did not bother me as much as they used to. For now, instead of hurting, all they did was wake me up in the middle of the night. And I am assuming they do that for everyone. Doors closing, dogs barking, babies crying, people talking to me on the phone, all these things were pain free for the first time in many, many years. I stopped carrying the earplugs around with me, and I began to wonder if all that work I put into rewiring my telephone was really worth it. (McKean, 1994, p. 81)

Attempts to deal with visually problematic situations include descriptions of the need to take seek out sensorially quiet situations or wearing dark glasses to minimise the effect of bright light:

This is my problem, not theirs, and I must deal with it. Yellow is a very common color, and I cannot dismiss it or avoid it entirely, however, much I may want to. ... But when things get too rough on me, I just retreat to my hotel room or some other "quiet" place for a while to slow

down and get my bearings. Then everything is okay again. (McKean, 1994, p.66)

If the lights were too bright, I could assume the uncomfortable role of an eccentric and put on dark glasses indoors. (Williams, 1994, p.73)

Authors describe a range of strategies to deal with tactile hypersensitivity. These included avoidance of 'new' experiences which might involve exposure to unpleasant events and adamant refusal using any means possible to avoid the unpleasant situation:

My teeth were very sensitive, and inside my mouth the consistency of some foods could be unpleasant, giving me a horrible feeling all over. With unknown food, you never knew what might happen. So if sometimes it was boring eating only skinless sausages and chocolate pudding, it was definitely worth it.  
(Gerland, 1997, p.14)

I flatly refused, and no attempts by my mother could change it. I was able to resist any threat or bribe. ... No one could prevail upon me. I would run away, scream, bite, scratch and claw-I would do anything. However far an adult was prepared to go to make me, I was always ready to go one step further. It was my terror that drove me, but they couldn't understand why the wretched child was so stubborn. 'For heaven's sake, surely you can stand a bit of pulling? If you want to look nice, you have to put up with a bit of hurt.' But the whole of me would be one great No. Other people, when they didn't want to do something, always seemed to have a little 'yes' or 'perhaps' tucked away somewhere. I exuded No through every pore. There was nothing else, only me and No, united and impregnable, with not the merest chance of anyone breaking in. (Gerland, 1997, p.102)

A number of authors recall situations in which others knowledge of these hyper-sensitivites were used to punish or bully them:

Now, years later, I know Miss Cray sensed my distress of loud noises. Such sounds not only startle autistic children but cause them intense discomfort. Like birthday parties. They were torture for me. The confusion created by noise-makers suddenly going off startled me. I would invariably react by hitting another child or by picking up an ashtray or anything else that was handy and flinging it across the room. ... Miss Cray, our governess, took advantage of my distress at noise. She used sound as a means of punishment. If I daydreamed, my spoon in mid-air, while eating lunch, Miss Cray would say, "Temple, eat. If you don't finish your soup right now, I'll pop a paper bag at you." She kept a supply of paper sacks on top of the refrigerator so that she could burst them in my face if I misbehaved or drifted away from the world of people(Grandin & Scariano, 1986, p.24-25)

Naturally, they were able to make fun of this characteristic, and naturally they could make fun of me. This was, after all, my own trick and my own fault, and as you make your bed so must you lie on it. So my mother thought up an 'It's all your fault' game, clearly a kind of bullying, but justified by the fact that it was all my fault. She didn't usually joke much, but now Kerstin had a chance to share something funny with her. They became allies in the game. It began by their calling out to me, and my not hearing them. Then my mother and sister would stand on the stairs whispering something about a bar of chocolate, or an ice-cream or a bag of sweets. I would hear their whispers, and want some too-I liked sweets a lot. But when I went to them, they just laughed. ... I was bewildered. The next day, they might stand outside my room and whisper about buns. I would feel just like a bun, and go out to them....They thought they had found an amusing way of attracting my attention. As they had kept on calling out and I hadn't answered, it was my fault. It must have been I who had driven them to make fun of me in that way.(Gerland, 1997, p.32)

One author does however, describe a 'positive' effect of sensitivity to sound: the need escape from it prompted an important breakthrough in the use of appropriate speech as a young child:

The telephone rang. And rang. And rang. No one answered it. The irritation and stress of the sound of that telephone jangling seemed to break through the barrier of my usual pattern of stuttering words. I ran across the room and picked up the receiver and said, "Hul-lo!" Alexander Graham Bell's first call couldn't have had more of a stunned reaction. (Grandin & Scariano, 1986, p.21)

### Variability

A number of accounts indicate a degree of variability in the experience of hyper-sensitivity. Two factors are identified by participants as impacting on the experience of hypersensitivity. One author clearly describes stress as impacting in a variety of ways on sensory functioning. This includes a temporary 'amplified volume/intensity' experience of sound, colour and brightness. Two other authors identify predictability as an important mediator in the extent to which sound may be experienced as problematic.

Shifting back and forth from one voice to the other, the pattern of speech changed continuously. It was too quick for me to keep up with any interpretation and it was getting out of sync. Mrs. Miller's patterns were just registering when Mr. Miller began to take over. My hearing started to climb, as though someone had turned up my volume, pitch, and speed controls. I covered my ears and tried to get a rhythm to calm down. (Williams, 1994, p.106)

When my parents were cross with me, they showed this by suddenly shouting out my name and the shouting made me feel frightened. Ever since then I have become frightened if somebody suddenly shouts out my name, although it is OK when I am expecting to be called and it is OK if it is said more quietly. (Jolliffe, Landsdown & Robinson, 1992, p.18)

However, in other situations where a fluctuating experience is described, authors offer no insights as to the processes which may be at work. Williams (1992) for example describes hypersensitivity to bright light but on another occasion suggests a very different impact:

I was completely lost . The place was far too big with too many walls, too many people and too many fluorescent lights. I went around everywhere turning them off. When I didn't they made me fall asleep. (Williams, 1992, p. 112)

McKean (1994) claims a highly variable experience of hypersensitivity in hands and feet:

Inanimate objects are another matter. There are times when I just can't touch anything because my hands feel like they are on fire if I do. Usually this just applies to certain textures, though I can't tell you which ones because they vary from day to day, hour to hour, minute to minute. It sometimes gets so bad that even the air circulating in the room hurts. Thankfully, this is rare. And I am only effected at the hands and feet. I have heard other cases where the person is effected all over. And I feel for them. As bad as it is for me, it must be very awful or even intolerable for them. (McKean, 1994, p.65)

The chewing surface of my teeth was occasionally incredibly sensitive to touch- almost electric-and seemed to be connected to a sensitive place at the back of my neck. This could be unbearable, and it helped to bite into something-preferably something fairly resistant to the teeth-then the pressure in my mouth evened up. Human flesh was the very best of all to bite into. I wanted to put my teeth into someone, an arm. I didn't know why. I just felt I needed to. ... I liked biting people, and on the odd occasion I was allowed to bite my big sister. But mostly I had to be content with things made of soft plastic-my old teething ring, toys, furniture . . . whenever I needed to calm that unpleasant feeling in my teeth, I bit into whatever was handy. (Gerland, 1997, p.14-15)

While the majority of accounts reflect a degree of attenuation in many aspects of hyper-sensitivity as they get older, the developmental course of this phenomenon is not straight forward and there is considerable variability. Gerland (1997), for example, recalls a short and time limited hyperacuity to smell and a more prolonged sensitivity in hair as developing in middle childhood

I actually thought it smelt peculiar for a long time after someone had got up off a chair, and I didn't want to sit down until the smell had gone. But there was no point in telling them that, because they would just go over and sniff and say with absolute certainty that it didn't smell of anything. So I preferred to stand up. This period when I sometimes stood at the dining-table because someone had recently sat on my chair didn't last all that long, perhaps six months. Then I no longer smelt any particular smells from chairs, and never thought about whether anyone had sat there before me. (Gerland, 1997, p.60)

At eight, I became over-sensitive to combs and hairbrushes, and I refused to have my hair done. Suddenly, I couldn't bear the pain that came from having my hair done. It seemed to burn like synthetic fire all over my head and the nape of my neck.(Gerland, 1997, p.102)

A number of other authors also describe continuing difficulties with sound hypersensitivity in adulthood.

This sensitivity to noise is common among adult autistics. Even today, sudden loud noises such as a car backfiring, will make me jump and a panicky feeling overwhelms me. Loud, high-pitched noises such as a motorcycle's sound, are still painful to me.(Grandin & Scariano, 1986, p.25)

Throughout my life, I have had as much difficulty in trying to understand sounds, as I have had in trying to understand words. I have come to this conclusion quite recently, as I am still frightened of



so many sounds that I cannot obviously be interpreting them correctly. The following are just some of the noises that still upset me enough to cover my ears up to avoid them: shouting, noisy, crowded places, polystyrene being touched, balloons being touched, noisy cars, trains, motorbikes, lorries and aeroplanes, noisy vehicles on building sites, hammering and banging, electric tools being used, the sound of the sea, the sound of felt-tip or marker pens being used to colour in, and fireworks. (Jolliffe, Landsdown & Robinson, 1992, p.14)

One author cites evidence hyperacuity for sound as having been confirmed by hearing tests.

Years later, I had my hearing tested again. At the time, it was found that my hearing was better than average, and I was able to hear some frequencies that only animals normally hear. The problem with my hearing was obviously one of a fluctuation in the awareness of sound. In this case it was as though awareness were a puppet, the strings of which were set firmly in the hands of emotional stress. (Williams, 1992, p. 40)

### **Hypo-sensitivity**

Where hyper-sensitivity was described as akin to an 'amplified intensity' experience, hypo-sensitivity may be described as a 'reduced intensity' experience. Hypo-sensitivity is described in relation to proprioceptive and kinaesthetic feedback, including pain, (Williams, 1992;1994); Gerland 1997), temperature (Williams, 1994); Mc Kean,1994), hunger (Gerland, 1997; Mc Kean, 1994) bowel and bladder signals \ (Gerland, 1997; Jolliffe, Landsdown & Robinson (1992) and whole body awareness (Gerland, 1997; Williams, 1994) and MacKean, 1994)).

### *temperature*

Slowly I had come to tell temperature better than before. I now pulled away sometimes under the hot tap and I felt a tingling sensation, which was called 'being burned', when I spilled boiling water upon myself (Williams, 1994, p.29)



*hunger*

I had no discernible feeling of being hungry, or not. I didn't know what I ought to eat. I didn't know how to cook anything, and sometimes I ate nothing at all. A pancake- type roll of soft thin bread or a pizza was the only cooked food I ate. Otherwise, crisps and Coca Cola were what I might have for breakfast, lunch or dinner. Whenever I forgot to eat, I would live on coffee and cigarettes for several days. (Gerland, 1997, p.183)

*bladder and bowel signals:*

I also had another problem, which required extending my lavatory strategies, though it was a problem I never understood until I was adult. I thought it was the same for everyone. I couldn't feel that I needed to go the lavatory, so I had to think out when I needed to go. I didn't know other people had a signaling system that warned them at intervals before the need to go became urgent. I had no such system. I felt nothing, nothing, nothing . . . - then it was urgent, then I felt it, and then I had to find a lavatory at once. So I always had to go beforehand and very frequently, so that it could never become that urgent. (Gerland, 1997, p.120)

I was frightened of the girls and boys, the teachers and everything there. I was frightened of the toilets and you had to ask to use them which I was not able to do, also I was never sure when I wanted to go to the toilet anyway and the teachers got fed up with having to take me to the nurse to change me. (Jolliffe, Landsdown & Robinson, 1992, p.13)

*Pain*

I had no inkling of the effect I had on other people, that they were provoked by my unmoved exterior. I was slapped and shaken and pushed by both my sister and the teachers, but I no longer felt any pain at all. In fact, my insensitivity to pain was by now as good as total.

Until then I had just been insensitive to certain pains, but now nothing hurt at all. And yet I felt-my actual feelings were not shut off-because when I was aware that I had injured myself somewhere, I could sense something, a non-pain, which branched out into my body from the place where the injury was. But the fact was, it didn't hurt (Gerland, 1997, p. 157)

My body was indeed very soft and supple, but I couldn't feel where the various parts of it were, or where they were in relation to each other. (Gerland, 1997, p.86)

*poor body awareness*

I experienced having an outer-body sense by seeing and hearing where my body was. My inner-body sense, like everything else, was mostly mono. If I touched my leg I would feel it on my hand or on my leg but not both at the same time. My perception of a whole body was in bits. I was an arm or a leg or a nose. Sometimes one part would be very much there but the bit it was joined to felt as wooden as a table leg and just as dead. The only difference was the texture and the temperature (Williams, 1994, p.228)

Authors accounts suggest that there is variability in this experience of hypo-sensitivity and that it does not relate to a total absence of awareness of sensation. Intense or particular 'hypersensitive' sensation is experienced;

I had been on painkillers for rheumatism, to be taken only when I needed them. The pains by now had become excruciating, and I would slam myself side-on into the walls and knock my head against them in an effort to ease the pain. Painkillers hardly seemed to help at all, and I felt as though my bones were grinding together in the same way that I would grind my teeth. (Williams, 1992, p. 57)

My teeth seemed to be the part of my body where I had the best feeling. Outside my body, I experienced feeling more diffusely. Only

vague information reached my mind when something or other happened; I needed to look at my body in order to know where I felt something. The further away from my head, the less the feeling. My feet were a white space on the map of my body. Although I otherwise found light touches difficult, the soles of my feet weren't ticklish as they are with so many other people. On the other surfaces of my body, light, soft touches tensed me, tightening the springs hard inside me and becoming unbearable. But under my feet that touch did not have the same effect. It was the only place where I could bear almost anything and actually like it, because I felt it so faintly. To be tickled with a piece of grass on my soles was the only little touch I could accept, the only little touch I experienced with feeling without being tormented by it. (Gerland, 1997, p.15)

Williams (1994) suggests that inability to recognise/ differentiate body signals and her ability to ignore them exacerbated or perhaps accounted for some of her difficulties with awareness of body states:

Sitting cheerily on the bus, I felt good with the sun coming through the window and warming my face. I had brought only a thin cardigan with me for this trip across two states and it was windy. I didn't mind so much. Even when physical sensation was present I was generally unable to tell cold from hunger or fear or needing to go to the toilet anyway. Generally they all felt the same, so I ignored the lot. (Williams, 1994, p. 152)

Perhaps I did not lack the feeling of hunger, or needing to go to the toilet, or needing to sleep. Perhaps my preoccupation with remaining a step away from fully conscious made it necessary for my mind to deny the awareness of these needs; certainly I would ignore the signs, feeling faint, anxious or grumpy, yet always too busy to stop for such things. (Williams, 1992, p.40)

In addition to these factors, another author highlights the role of her social-communication difficulties in her lack of reactivity to pain:

I thought that a strange rule, but I fell in with it. School was full of things I didn't grasp, and I simply had to comply with them. The boys told me to go with them to the lavatories, which were down in the basement, entered directly from the playground. In there, I was given a punch in the stomach, every day, though usually only one. Perhaps I wasn't much fun to hit because I had a very high pain threshold, and even when it did hurt I never showed what I felt. I didn't know that was what you should do (Gerland, 1997, p.92)

In addition to the consequences outlined above, one author identifies how poor body awareness and the resulting lack of a sense of physical self, contributed to terrifying fear of the dark in childhood:

Pia found out that what really terrified me was to be shut inside the school store- room. The light- switch for the store-room was on the outside, so when she shut me in, she switched the light out too. There I was in the pitch dark with no night vision, so my eyes couldn't gradually get used to the dark or distinguish a little more. They seemed to have been taken away from me, and I lost all sense of where I was inside that room. I lost my body. The up and downness of things vanished. I couldn't feel what was me and what was the room. It was somehow as if I had totally changed substance, perhaps been turned into gas. A kind of dissolving. (Gerland, 1997, p. 74)

A number of authors describe attempts to remediate aspects of this under-reactivity in adulthood with greater or lesser degrees of success:

For a while, I was going to an occupational therapist every Monday from 10:00 a.m. to 11:00 a.m.. This is something else that worked. Sensory integration exercises left me feeling very whole and complete. I wish I could go back again. I have lost the feeling of whole and complete since I have left.  
(McKean, 1994, p.72)

I worked on getting some inner sensitivity in my legs, arms, face and torso, which I often felt no connection to. I brushed my body, despite tears, despite deadness, and despite the sad realization it belonged to me in spite of the feeling that it didn't. ... I moved my hand to my arm and fearfully whispered, 'I've got an arm.' I felt it not on my hand from the outside, as usual, but from the inside. My arm had felt it from the inside. 'Arm' was more than a texture; it was an inner sense. It was foreign, and the foreignness was frightening. I felt like an alien suddenly acquiring humanness. I was a stranger in the vehicle that carried me about but which was only now telling me it was here, it was real, it was mine, and it was part of me. I felt my hand, then my forearm, then my upper arm.

...I walked across the floor like someone trying out new legs. I felt the distance between my shoulders and my feet. I knew how big I was, enclosed within the space of my own whole body. 'Oh my God, I'm so short!' I squealed in a surprised whisper. 'I am not big at all!' I had always had the impression that I was as big as whatever person I was with, and, at five foot two inches tall, most of them were bigger than I actually was. If I was with short people, I assumed I must be a short person. If I was with tall people, I assumed I must be a tall person. In the absence of an inner body sense, they had been my mirrors, my external 'map'.(Williams, 1994, pp. 228-230)

### **Other Sensory Irregularities**

A number of other anomalous sensory experiences are also described in these public accounts. These include descriptions of generalised sensory pain (Mc Kean, 1994)), intense unpleasant sensation in a specific area of the body (Gerland, 1997) and need for deep-pressure touch (Grandin & Scariano, 1986; Mc Kean, 1994; Gerland, 1997) and synaesthetic-type experiences (Gerland, 1997). These problems are described as having had or as continuing to have a very significant impact on their lives.

*generalised pain*

There is a constant, low-intensity pain going through me at all times. Sometimes it is not so low-intensity. And there are many things that I want to do, many things that I know that I should be doing, and sometimes I cannot do these things because I have to put that energy into dealing with this pain. This I find to be very frustrating. (McKean, 1994, p. 63-64)

*unpleasant sensation in spine*

All the time I was growing up, I suffered from an almost constant shudder down my spine. Periodically, the shuddering grew worse, while at other times it kept relatively quiet so that I was able to live with it. It was like that feeling the moment before you sneeze, only as if it had got stuck and was suspended inside my spinal cord in order to turn into something permanent. The shudder that wasn't really a shudder must be released, then ought to be registered on the Richter scale. I so much wanted it to happen, just as your body wants to sneeze when a sneeze is on the way. But the feeling was there to stay, an eternity of eternities. I became slightly used to it, but it was a constant torture, most noticeable when it changed in intensity. With a wealth of inventiveness, I was able to alleviate it a little at times, but never entirely (Gerland, 1997, p.57).

*Craving for deep pressure touch*

I think for me the most aggravating problem would be the pressure cravings. If I did not have to put so much of my energy into dealing with this, I could get a lot more done every day (McKean, 1994, p.63).

These authors articulate different explanations for the need for deep-pressure touch. Mc Kean (1994) links the need for deep-pressure touch with the low level sensory pain already described, with pressure helpful in alleviating this discomfort. Gerland (1997) suggests that deep-pressure touch has a calming and satisfying effect . Grandin & Scariano (1986) attributes her pressure



craving in general terms to a need for 'soothing' tactile stimulation in a damaged nervous system resulting from an inability to tolerate people touch:

In the second grade I began dreaming about a magical device that would provide intense, pleasant pressure stimulation to my body. In my imagination this wonderful machine would not be a substitute for Mother's hugs, but would be available at any time to soothe me. As an adult, I know now that my childish visions of a magic machine was my search for a means to satisfy my damaged nervous system's craving for tactile stimulation. Since the governess, who lived with us from the time I was three until I was ten years old, never hugged or touched my sister or me, I craved tender touching. I ached to be loved-hugged. At the same time I withdrew from over-touch as from my overweight, overly affectionate, "marshmallow" aunt. Her affection was like being swallowed by a whale. Even being touched by the teacher made me flinch and draw back. Wanting but withdrawing. There is a balance in teaching the autistic child the joy of touch and panicking the autistic child with the fear of engulfment (Grandin & Scariano, 1986, p. 32).

These authors describe a range of strategies which they pursued to alleviate these difficulties which include use of 'brushing' to alleviate sensory pain; repetitive rubbing and touching to reduce spinal sensation and various strategies to meet the need for deep-pressure sensation:

Brushing. I strongly advocate the use of this technique. I think this may help! This is a process by which a surgical brush is used to stimulate the tactile senses by brushing the arms, legs, and back of the individual. The result for me is a loss of sensory pain for approximately 45 minutes to maybe an hour. It is nice to be able to move without pain.(McKean, 1994, p.51)

I never told anyone it felt like that. I didn't know it could be any other way, and I had no words with which to describe my torment. Such words didn't exist. I had become used to it, but when it got worse, when the pressure increased, I had to do something to quieten it.



Rubbing my hands together could help, and pressing my back and the nape of my neck hard against a wall could also relieve it. Sometimes it helped a little to jerk my head. I had to feel my way ahead and try to find ways that might alleviate it. ... I began to develop compulsive rituals. By running the tips of my fingers or pressing the palm of my hand against something, the shuddering might first increase but then reach a point where I no longer felt it so acutely. As if I could raise its frequency so that it lay beyond what I could perceive (Gerland, 1997, p.57).

But, as a child, since I had no magical, comfort device, I wrapped myself in a blanket or got under sofa cushions to satisfy my desire for tactile stimulation. At night I tucked in the sheets and blankets tightly and then slid in under them. Sometimes I wore cardboard posters like a sandwich board man because I enjoyed the pressure of the boards against my body. (Grandin & Scariano, 1986, p. 33)

Another thing I do to deal with the pressure cravings is put on the Pressure Suit. This is a device designed by Michael, Gwendolyn, and myself. It consists of a tight scuba suit and a life jacket. The life jacket goes on under the scuba suit to give it more pressure. The valve on the jacket is located in a way that you can manually adjust the pressure, increasing or decreasing it at any time while it is under the suit. While this does work, it presents its own problems. First, since the suit does not "breathe," it is easy to get very hot (and quickly uncomfortable). Also, I have noticed that it is generally not a good idea to walk around in public in a scuba suit. ...My thanks to Michael for the idea, and for donating the suit to Thomas. The low-intensity sensory pain is gone while I am wearing it. (McKean, 1994, p.65)

It was preferable if it was absolutely tight all round me, and at sleep time it was best if I could get father to fold the mattress round me, then fasten the sheet firmly around it so that I was lying in a tight roll of mattress. But at home there wasn't always someone available who

would agree to do as I wanted, or who had time to (Gerland, 1997, p.105)

It is clear from the accounts of Grandin & Scariano (1986) and McKean (1994) that the pursuit of ways to meet the need for deep-pressure touch became the focus of much creative endeavor. Gerland's (1997) account on the other hand suggests that her need for deep-pressure sensation was a much less dominant drive in her life. Grandin & Scariano's (1986) search for a machine to deliver the pressure she craved became a childhood fixation:

Another idea I had in grade school was to build a small enclosure about three feet wide and three feet tall-just big enough so I could get into it and close the door. This miniature enclosure would be heated. Warmth along with pressure was important in most of my imaginary designs. Recent research indicate that certain stimuli and stereotyped behavior seem to reduce arousal. Warmth and pressure tend to lessen arousal, especially in a damaged nervous system. Perhaps if I had had a magical comfort machine, I could have used its warmth and pressure instead of throwing a temper tantrum. My imaginary designs were a fixation-an obsession that was refined and improved with each imaginary, magical machine.(Grandin & Scariano, 1986, p.34-35)

In adulthood Grandin & Scariano (1986) designed and constructed a 'Squeeze Machine' to deliver the pressure she craved. She suggests that this had a significant effect on her receptiveness to positive emotion and reduced her aggressive feelings:

First, I adjusted the headgate to accommodate the height of my head when on my hands and knees and then I climbed into the enclosure. Ann pulled the rope which pulled the sides of the squeeze chute together. Soon I felt their firm pressure on my sides. Ordinarily, I would have withdrawn from such pressure as from the engulfing embrace of my overweight, marshmallowy relative during childhood days. But in the cattle chute withdrawal wasn't possible. No way could I avoid the pressure unless I was released from the squeeze chute. The

effect was both stimulating and relaxing at the same time. But most importantly for an autistic person, I was in control-unlike being swallowed by an overaffectionate relative, I was able to direct Ann as to the Comfortable degree of pressure. The squeeze chute provided relief from my nerve attacks. True to form, I became fixated on it. (Grandin & Scariano, 1986, p.91)

Although the squeeze chute was just a mechanical device, it broke through my barrier of tactile defensiveness, and I felt the love and concern of these people and others. It was as if an accordion folding door had been shoved back revealing my emotions.... Through the use of my squeeze machine I learned to control my aggression and to accept affection. ... Aggressive, negative thoughts were difficult because the soothing feeling made aggression melt away. (Grandin & Scariano, 1986, p.96)

McKean (1994), unlike other authors, suggests that tactile stimulation delivered through 'people touch' is similarly soothing and helpful in restoring what he calls 'sensory equilibrium'.

In the tactile area, my problems seem to be the exact opposite of what autism is reported to be. This leads me to believe that the sensory problems in autism are those of an extreme, one way or the other. Where most find touch to be painful, I find it to be very soothing, and even necessary. It provides for me a sense of "sensory equilibrium." I find everything inside to slowly move back into focus. This also presents problems as our contemporary American society has strict rules on touch. And very few people are even willing to acknowledge that platonic affection even exists. So it is often misinterpreted.(McKean, 1994, p.65)

Gerland's (1997) account indicates that the unpleasant sensation in her spine which was a constant feature of her childhood did disappear for a lengthy period in her adult life but had more recently returned again. In addition she now feels she is more able to tolerance the unpleasant sensation:

I thought that steady shudder down my spine had also gone, but during this last year it has come back. It went away for many years- it must be ten years since I last felt it. To cheer myself up, I tell myself that perhaps certain symptoms to do with this handicap will appear again as I develop and get better. Though I don't really know for sure. Anyway, I can now deal with the spine shudder. I am grown up and I can reason with myself about what I feel and what I shall do about it. Sometimes a hot shower can help. At other times, it's a matter of just putting up with the feeling until it goes away. (Gerland, 1997, pp. 250-251)

### *Synaesthetic experience*

Gerland (1997) reports what might be considered forms of synaesthetic experience. Touching metal jewellery [also a source of great and irrational fear], is described as triggering perception of sound. In addition her own and others' emotion was perceived in terms of colour.

If I was made to touch jewellery, I felt a sharp whistling metallic noise in my ears, and my stomach turned over. Like a note falsely electrified, that sound would creep from the base of my spine upwards until it rang in my ears, tumbled down into my throat and settled like nausea in my stomach. These physical sensations produced by jewellery frightened me, and I transferred that terror on to the jewellery itself, so that the very sight of it terrified me. ... And brown metal hairclips with horrible little plastic bobbles at the ends were awful, too. They made a sound when you took hold of them-a metal sound that jarred with that smooth, slippery, transparent stuff, the plastic. It was horrible and dangerous, and it hurt inside. And rings with nasty shiny stones in elaborate settings, they also jarred with each other. I hated the slippery shiny sound, and the sharply convoluted setting was painful to me. The convolution didn't stay still so that you

could really see what it was. It seemed to be crawling with something. (Gerland, 1997, p.54)

Gerland (1997) describes her childhood perception of emotions in self and others in terms of colour. In the absence of other knowledge, this system of colour codes was in childhood used as one way of making connections between events and places:

My state was just one colour inside myself. I was the only one who had colours: I had an internal colour system which became a way of connecting information about different worlds, about the nursery world and the garden world. Everything became a colour inside me-people, words, feelings, atmospheres. Not understanding was faintly orange, a pale orange with sunlight coming through it. Tiredness, what I hadn't the energy to try to understand, came and laid a dark green on top of the orange light and put it out. The dining-room world, the kitchen world and the hall world-none of these had anything to do with each other until a colour made me connect. If my mother said something in a violet-coloured way in the kitchen and two months later used that violet tone of voice in the bathroom, I suddenly realised that the kitchen and the bathroom had something to do with each other, so I could begin to find other similarities such as that there was water in both rooms. But the first connection was always via colours. (Gerland, 1997, p. 21]

It often helped to have all these colours connecting the different bits of life together, but sometimes it caused problems. I might have great difficulty letting go of the idea that two things belonged together because of the colours, although I hadn't found any other common denominator. Then great amounts of energy would go on trying to find something that would clarify the connection. Perhaps those things really did have nothing whatsoever to do with each other. (Gerland, 1997, p.22)

### ***Sensory-based world***

There is strong support for the notion of a primary attentional orientation to the physical and sensory world rather than the social world of people.

Authors describe an early childhood experience of the world which is attuned to and rooted in the physical and sensory environment and in which there is a corresponding lack of intuitive connectedness to people. This is described as a self-contained or 'own' world, separate from the 'real' or 'outside' world of people. Conceptually the 'separateness' of this early sensory-based world is understood as linking with the tendency to an over-narrowly focused attentional beam which is also described in these accounts.

Authors describe an early experience of the world in which awareness, interest, curiosity and exploration are embedded in detail of the physical and sensory world. There is a sense of immersion, of pleasure and contentedness in a world of physical and sensory experience without reflection on meaning or function.

I remember my first dream—or, at least, the first that I can remember. I was moving through white, with no objects, just white, although bright spots of fluffy colour surrounded me everywhere. I passed through them, and they passed through me. It was the sort of thing that made me laugh. This dream depicted the nature of my world at that time. Awake, I pursued the dream relentlessly. I would face the light shining through the window next to my cot and rub my eyes furiously. There they were. The bright fluffy colours moving through the white.  
(Williams, 1992, p.3)

I can actually remember lying awake in my cot, along with what my cot looked like. I can remember being very interested in the colors in a picture which had been stuck on the end of my cot. Although I can still remember what this picture looked like, I never actually understood what it was portraying at the time. (Jolliffe, Landsdown & Robinson, 1992, p.12)



This sensory based world is described as a self-contained world distinct from the social world. This experience is characterised by a sense of timelessness and absorption in detail. In a number of accounts people are first described in terms of their intrusion or impact into this a-social world.

I got enormous pleasure from throwing things into a big tree in our backyard. It didn't matter to me what shape or size the object was—I took toys out of the sandbox or things from the kitchen (if I could sneak in and grab something) and threw them all into the tree. I wanted to see how high they would go and where they would get caught. I loved the pattern: throwing the object as high as I could, seeing where it hit the tree, following its downward movement with my eyes, and watching where it got stuck. Sometimes, though, I'd look away after I made the throw and just listen to the sound it made as it fell rustling through the leaves and branches. I loved doing this so much that I kept throwing the same thing into the tree over and over until it stayed there, even if it took forever. While I was doing it I had no sense of time— hours passed but I didn't notice. When Mom saw me playing this game and tried to stop me, I got really furious with her and thought, "How dare she keep me from doing what I want to do!" It gave me a feeling of security and a lot of pleasure no matter how much I did it. I wasn't trying to hurt anyone; I was in my own world, and whatever else went on nearby, I was not aware of it. (Barron & Barron, 1992, p.44)

There is a strong sense of lack of intuitive connectedness with people and a preference for the non-social world:

I spent a great deal of my time alone in my bedroom and was happiest when the door was closed and I was by myself. I cannot remember ever thinking about where my mother, father, brother and sister were. They did not seem to concern me. I think this was because I did not for a time realise that they were people and that people are supposed



to be more important than objects. (Jolliffe, Landsdown & Robinson, 1992,

I discovered the air was full of spots. If you looked into nothingness, there were spots. People would walk by obstructing my magical view of nothingness. I'd get past them. They'd garble. My attention would be firmly set on my desire to lose myself in the spots, and I'd ignore the garble, looking straight through this obstruction with a calm expression soothed by being lost in the spots. (Williams, 1992, p.3)

However, Williams (1992) suggests that where people were willing to enter into or cater for her interest in a detailed physical world, this formed the basis of some level of connection and trust:

My grandfather fed me sultanas and biscuits, piece by piece. He made up special names for everything; he sure knew his audience. He understood my world and so was able to make me fascinated with his. He had some liquid mercury balls which he would splatter into tinier balls and make them chase one another. He had two minute magnetized 'Scottie' dogs, which he would make chase one another. This sort of chasing was safe. Communication via objects was safe.... My father catered to my fascination for small fancy things and shiny objects. He would bring me something different every week and would always build me up by asking me if I knew how special and magical these various bits and bobs were. I would sit on his knee, my eyes fastened to the object, listening to the story as though he were one of my storytelling records.(Williams, 1992, p.5-6)

A number of authors recall their knowledge and evaluation of people from this time primarily in terms of their physical or sensory characteristics:

I still remember the smell of my grandmother. She wore chains around her neck. She was soft and wrinkly, wore knitted things that I could put my fingers through, had a husky laughing voice and smelled of camphor. I would take camphor off the shelves at the supermarket,

and twenty years later bought bottle upon bottle of eucalyptus oil and spread it around my room, corner to corner, to keep out everything else except for the comforting feeling that association gave me. I collected scraps of coloured wool and crocheted bits and would put my fingers through them so that I could fall asleep securely. For me, the people I liked were their things, and those things (or things like them) were my protection from the things I didn't like - other people. (Williams, 1992, p.5)

My fear got worse when I saw Dr. Rossi. What scared me most was his bushy beard, and the fact that it was a dark beard bothered me too. He had a lot of dark features, in fact— his voice, his hair, his skin color, and his clothes. All of these things made me uneasy, but it was the beard that was the focus of my fear. (Barron & Barron, 1992, p.53)

The a-social world is described as having high emotional significance and resonance, providing a range of emotional experiences. Authors describe a sense of congruence, belonging, comfort and security arising from their immersion in this sensory world and intense pleasure in particular objects or activities.

My love for curved things began early, long before it became so vital to hold them. I liked bends—they were so soft and, well, curved. I felt a need for them and they gave me some kind of satisfaction. A curved thing had something calming about it, a wholly obvious feeling. A curved thing was calming in the same way as green was green—so obvious it was impossible to explain. (Gerland, 1997, p.11)

I really loved to look into car windows at the speedometer; my real interest was the red needle. I tried to see as much of the needle as I could— this gave me a strong feeling of joy. I especially liked looking down at the speedometer, because that way I could see more of the needle. (Barron & Barron, 1992, p.87)

Despite this I can read music and play it and there are certain types of music love. In fact when I am feeling angry and despairing of everything, music is the only way of making me feel calmer inside.(Jolliffe, Landsdown & Robinson, 1992, p.15)

In contrast to this sense of congruence and order, interactions with people are described as frequently producing a sense of anxiety and bewilderment.

My mother and I were now left to ourselves in the daytime, totally without any common language. She had some kind of vague, indistinct language, filled with 'in a minute', 'maybe' and 'later', and mine was concrete and exact. I mostly didn't grasp what she meant, and she almost never understood that I meant just what I said. This resulted in my sometimes having violent outbursts of temper and throwing things about. When I didn't have these outbursts, I would go and sit behind furniture or get under beds. I would pick at the material with my nails, liking the feel of the rough surface. I also liked being in small cramped spaces where it was quiet and calm, especially when I fitted exactly into the space. I wanted to put on a space, put on a sort of cave, like a garment-it felt safe when it was cramped. There were to be no gaps between things, and when I fitted into something exactly, a calm came over me.(Gerland, 1997, p.24)

Lack of intuitive connection with people is reflected in particular difficulty in a number of social interaction and social -communication skills. These include difficulty in making direct eye contact, and [with the exception of Mc Kean,(1994)] and in dealing with close physical contact and affection:

Looking at people's faces, particularly into their eyes, is one of the hardest things for me to do. When I do look at people I have nearly always had to make a conscious effort to do so and then I can only do it for a second. If I do look at people for longer periods of time, they usually claim that I seem to be looking just through them rather than at them,

as if I am unaware that they are actually there. People do not appreciate how unbearably difficult it is for me to look at a person. It disturbs my quietness and is terribly frightening - though the fear decreases with increasing distance away from the person. (Jolliffe, Landsdown & Robinson, 1992, p.15)

I don't particularly like being touched - touch is not pleasant to me at all generally unless I'm well warned in advance that I'm going to experience this sensation otherwise I don't like it and people were touching me and pulling me around in those days like they do with all kids and I started reacting badly to it

The impact of this difficulty with physical closeness varied among authors. For Jolliffe, Landsdown & Robinson (1992) it led to difficulties with many forms of physical closeness. However, Williams (1994) differentiated between 'instrumental' and affectionate or emotionally meaningful touch;

When I was young I hated my hair being brushed and washed, my teeth being cleaned and my nails being cut. I did not like people anywhere near me and I was cross that my quietness was being disturbed. However, if parents are sure that their child is not actually frightened, they should be very insistent for these are essential things to be done. (Jolliffe, Landsdown & Robinson, 1992, p.18)

I had previously worked in child care. Picking the children up and clothing or feeding them involved what I called 'instrumental touching'. I handled it as I did when I resigned myself to letting a doctor or dentist examine me. It was a category of touch that was dealt with by the part of my mind that was purely clinical, purely logical, purely responsible: Willie. There was nothing social or emotional about this form of touch; we were both objects. (Williams, 1994, p.126-127)

I had always experienced being touched emotionally as the threat of death. The tremors associated with this were equivalent to having been

in a near-death situation where the only thing your mind is saying is 'Get me out of here; I'm going to die'.(Williams, 1992, p.152)

A number of authors perceived a lack of control in their interactions with people. Conversely being in control is identified as an important element of the security of the non-social world:

On the other hand I tend not to like kisses, hugs and cuddles very much. If I do give anybody a hug and cuddle it has to be when I feel like it, not when they want it. (Jolliffe, Landsdown & Robinson, 1992, p.15)

When Mom called me I would suddenly get scared because I knew I would be yelled at once again for doing something I enjoyed. This was my world and I was in control—I controlled the object; it went up into the tree because I made it do so—and if the thing I was throwing belonged to somebody else, it didn't matter to me or even have anything to do with me. When I got yelled at or punished, I felt as if I were being invaded; I was no longer in control— someone had control over me again.(Barron & Barron, 1992, p.45)

A number of authors describe a sense of bewilderment or anger that the people world showed little understanding of and respect for their attachment to the physical world and the security which it provided

To the world around me, my behaviour was utterly incomprehensible. I kept touching things all the time- poking my fingers into or under bottles, sofa arms and door- handles, rubbing my palm against turned banisters. I simply had to touch all these things that had the curve I needed. But no one around me had any idea it was the curve in particular that was the common denominator in everything I had to touch. I did nothing but a whole lot of strange and irritating things. I didn't know that what I was doing was odd and annoying to others.

All I knew was that what I did, I did out of necessity, vital necessity. And that in the eyes of the world around me, this aroused no respect. (Gerland, 1997, pp.11-12)

Most streets just kept going on forever, but I loved the dead-ends because they made me feel safe. Every time we approached one my anticipation would skyrocket. Then what happened? Our car would pass right by! My parents would refuse to turn into the street. I hated that and I got so angry and resentful! It infuriated me when all I wanted was to see the end of a street and they wouldn't let me. All I asked was that they take me up the street, and they wouldn't even do it! I felt deprived of something I really loved; besides, I had to rely once again on someone else to take me, someone else in control. At least if I

wanted to throw my play phone into a tree, I could toss it up there on my own! The car was not in my control, so once again Barron & Barron (1992) could not get what he wanted! I felt tremendous inadequacy and that made me very, very angry. (Barron & Barron, 1992, p.90)

This strong orientation to the immediate physical world and the lack of intuitive connection with and understanding of people leads to the absence of a shared social framework in which to embed experience and the absence of shared meaning and interpretation. This in turn is viewed as leading to an 'in the moment awareness' and absence of informed reflection on experience. It contributes to an over-physical or idiosyncratic framework of interpretation of meaning and connection between events often based on association. The authors describe a number of consequences including examples of false beliefs about the world, including erroneous beliefs about people and objects, failure to generalise or over- generalisation from experience, that led to upset and distress for them and for others.

As my visual impressions were very clear and sharp, I connected whatever happened with what I could see. To me, everything boiled down to what I saw, and sight was the most reliable of my senses. It



was as if my sight was tangible. I desperately wanted to understand, and this led to theories: if everything looked in a certain way in the living room-the sun shining in through the curtains, the ashtray on the table with a newspaper beside it-and if Kerstin then came back from school . . . I thought that everything had to look exactly the same the next day, for her to come back from school. It quite simply had to be like that. And in fact, it often was. (Gerland, 1997, p.26)

Sometimes it was all so incomprehensible, I couldn't even find an end in the tangle to pull at. Then I would turn in on myself, knowing neither the question nor the answer; and I couldn't tell anyone. My state was just one colour inside myself. I was the only one who had colours: I had an internal colour system which became a way of connecting information about different worlds, about the nursery world and the garden world. Everything became a colour inside me-people, words, feelings, atmospheres. Not understanding was faintly orange, a pale orange with sunlight coming through it. Tiredness, what I hadn't

the energy to try to understand, came and laid a dark green on top of the orange light and put it out. . . . The dining-room world, the kitchen world and the hall world-none of these had anything to do with each other until a colour made me connect. If my mother said something in a violet-coloured way in the kitchen and two months later used that violet tone of voice in the bathroom, I suddenly realised that the kitchen and the bathroom had something to do with each other, so I could begin to find other similarities such as that there was water in both rooms. But the first connection was always via colours. It often helped to have all these colours connecting the different bits of life together, but sometimes it caused problems. I might have great difficulty letting go of the idea that two things belonged together because of the colours, although I hadn't found any other common denominator. Then great amounts of energy would go on trying to find something that would clarify the connection. Perhaps those things really did have nothing whatsoever to do with each other. (Gerland, 1997, pp.21-22)



Several authors describe erroneous beliefs about the nature of objects and the nature of people. In the early childhood years a number of authors gradually became aware that people were different from other objects:

Eventually I distinguished people from things and nature, and came to think of them as people- objects: second-rate, distant, difficult to comprehend but usable.(Williams, 1994, p.68)

Similarly a number of accounts reveal false beliefs about the nature of objects:

My feet made indentations on the carpet as I walked across it. It obviously felt I was there. 'Hi carpet,' I said, glad to be home. My bed was my friend, my coat protected me and kept me inside, things that made noise had their own unique voices which said vroom, ping, or whatever. Windows looked outside at the day, curtains kept the light from coming inside, trees waved, the wind blew and whistled, leaves danced, and water ran. I told my shoes where they were going so they would take me there. A tin came down from the shelf. I laughed. It looked like it was committing suicide as it suddenly jumped away from the wall. Things never thought or felt anything complex but they gave me a sense of being in company ... Everything had its own, if limited, volition. Whether a thing was stationary or movable depended more on the thing's readiness to move than on the person's decision to move it. Statements like 'it won't budge' only confirmed this assumed reality. It had never occurred to me to ask myself how objects knew or felt, nor was I interested. For me it had been an unquestioned assumption.(Williams, 1994, p.65)

My goal was to see all the buses the school owned in one year so I could compare all of them. I loved the way they looked when they were all parked in a line, and I got very angry when bus 24 was late and I had to go home before I saw it. It was not supposed to do that! It was supposed to be in that line with the other buses. I hated it because it behaved the worst and was often late.(Barron & Barron, 1992, p.108)

Authors describe a gradual move towards a more meaning based social world experience over the course of childhood. Despite growing openness to and understanding of the 'real' world as they get older, the authors describe a continuing emotional salience for the physical and sensory world and a continuing tendency for their attention to be drawn in this direction.

I used to really enjoy, and still sometimes do, looking at lights (but not very bright ones, like those used by photographers), shining metal and anything which sparkles, I also like spinning objects and watching them spin and enjoy the feel of certain surfaces. (Jolliffe, Landsdown & Robinson, 1992, p.13)

I looked through the many bags and tins of little treasures which I had packed for transportation in a tea-chest. I piled in bits of coloured tin foil, buttons, ribbons, sequins and bits of coloured glass which had been with me all my life. In the end the tea-chest lid wouldn't go down, and I sorted through all of my bits several times before weeding out the ones I was most taken by or attached to .... The places, experiences and people I had become attached to, my sense of security and my ability to make sense of the relationships between things existed within these collections. I could lay everything out in categories and grasp the concept of order, consistency and belonging despite my inner lack of it. I could see what role each thing had in relation to the next, unlike my relationships with people. Unlike my life, all my special things had their own undeniable place within the scheme of things.

(Williams, 1992, p. 146)

However, a number of authors describe the dilemma and pain of trying to straddle both the social and sensory worlds. Intense pleasure in and attachment to objects is judged odd and inappropriate, a further source of 'difference' in the real world:

I wanted to know why people laughed at me. I knew I was funny but I didn't know why. 'Give me an example,' said Dr. Marek. I gave him the example of a reaction to my reaction over a pair of shoes. They were shiny patent leather and cost five dollars. I thought they were wonderful. I loved the smell, the smoothness, and the shininess. They looked edible. I had smelled them and brushed the smooth surface along my cheek. I carried them in my arms looking at them as I walked along. The person with me watched. My companion looked sort of sad but smiled a bit. 'Are they your best friend?' I was asked. I thought about that strange expression. I came to wonder if this person somehow felt sorry for me and I wondered why she would.(Williams, 1994, p.64)

Williams(1994) also describes an internal conflict between the allure and comfort of a purely sensory experience which provided a retreat when she struggled to make sense of the real world, and the need to persist in her battle to make sense of the social world in order to make herself more effective within it.

I was sick to death of my attention wandering onto the reflection of every element of light and color, the tracing of every patterned shape, and the vibration of noise as it bounced off the walls. I used to love it. It had always come to rescue me and take me away from an incomprehensible world, where, once having given up fighting for meaning, my senses would stop torturing me as they climbed down from overload to an entertaining, secure, and hypnotic level of hyper. This was the beautiful side of autism. This was the sanctuary of the prison.(Williams, 1994, p. 113)

Belonging to the 'real' world is described as requiring the loss of the sensory world and the beliefs which had supported it:

My world was beautiful,' said Susan. 'It was full of colors and sounds. There were no people in it,' she said matter -of-factly. 'One day I made

a friend. That's how I lost my world.' I asked her how this happened. 'Well, when I was five I became interested in the way my friend did things and more and more I stopped visiting my world and I lost it,' she explained. ... 'I remember my own world very well,' she said. 'I used to try to share it with kids as I was growing up but they didn't understand it. They thought I was silly or mad. In the end, I gave up and decided just to be like everyone else. (Williams, 1994, p.196)

In one great swoop, my perception got knocked off its feet and I fell into a perceptual black hole. Dr. Marek gave me a rule with no exceptions. He explained that things need a nervous system in order to think or feel. Back in my apartment, I tapped the wall. Every time I held onto a curtain, every time I looked at my shoes, a new perception of objects as dead things without knowledge, without feeling, without volition, nagged at me. I felt my own aloneness, with an intensity I had always been protected from. ... Everything around me had no awareness that I existed. I was no longer in company. I felt trapped by an impending acceptance of a new logic my mind couldn't continue to deny. My infantile emotions could not bear it. I wanted to run back into 'my world' but it had been bombed. ... I paced like a lion in a cage. ... I realized I'd lived my life in a world of object corpses. ... I made a rule that there would be three things immune to this new logic of objects; my travel companions, two stuffed toys called Orsi Bear and Travel Dog, and my reflection. (Williams, 1994, pp.67-68)

As adults both Barron & Barron (1992), and McKean (1994) describe a continuing vigilance to avoid the pitfall of returning or regressing into this tempting world of childhood:

A year after I moved back to Youngstown, Mom and I were having lunch at a health-food restaurant when suddenly I heard a too-familiar sound. Excitedly I peered out the window as several school buses passed by. "What numbers are they?" Mom asked, smiling at me. I felt hot with terror and nausea. I was reverting to my old, uncontrollable behavior! I said defensively, "It's not like that—I'm not thrilled by

those buses the way I used to be! I'm not interested in them!" She nodded and seemed to agree with me. ... Like a recovering alcoholic who can't have alcohol in the house, I don't own a deck of cards because I still find the temptation to "play buses" too great. I am on guard against old habits that lure me into old behaviors (Barron & Barron, 1992, pp. 255-256)

I find I am on guard at all times. The only time I am not is when I am with only the closest friends. And even then, the shields never go all the way down. For if they were to go all the way down, I would be forced to retreat against my will into the world I created for myself long ago. A world where everything is okay, and there is no reality. By setting up these defenses, the children are only protecting themselves. And I feel that they have every right to do that.  
(McKean, 1994, p. 50)

### ***Disordered Attention Beam***

Evidence from first-hand accounts both supports and illuminates the notion of a disordered attentional beam. As conceptualised the attentional beam is regarded as a dynamic 'spotlight' the intensity and breadth of which will determine what sensations and sensory events enter one's attentional focus or awareness. Smooth, automatic narrowing and widening of this beam is considered essential for efficient processing of and responding to significant events (both internal and external) within the sensory environment. Failure in this automatic, dynamic adjustment is conceptualised as leading to problems in sensory processing and responding. An overly-narrowed beam is conceptualised as leading to a lack of adequate awareness of and response to significant events within the environment outside of the particular event being focused on. An over-widely or diffusely focused beam is conceptualised as leading to a difficulty in filtering out extraneous stimuli or 'selective attending' to particular events in order to make sense of them. In the absence of this automatic and dynamic adjustment, attending to and making sense of the world becomes inefficient, effortful and problematic.

Analysis of firsthand accounts provides evidence supportive of the notion of impairment in the efficient, automatic and dynamic adjustment of this attentional beam. The analysis confirms the tendency of these individuals to function at extreme attentional positions of an over-narrowed or an over-widely focused beam leading to a range of difficulties in reliable awareness of and response to the flow of events around them. Managing this disordered beam is described as effortful and problematic and the process is subject to the influence of a number of environmental and within-person factors.

### **Over-narrowed beam**

An over-narrowed attention beam as conceptualised is strongly characteristic of the early childhood years. Analytically this characteristic is closely bound up with the concept of an attentional orientation to the physical and sensory world which is also reflected in authors descriptions of their sensory-perceptual experiences particularly in the early childhood years. Aspects of sensory-perceptual experiences described by the authors which are considered to reflect this over-narrowed attentional beam are described below.

The authors describe an early childhood experience in which they had little awareness of the world outside of themselves and their immediate activity. Several authors allude to a different consciousness, a 'my world' existence which was separate from 'the world'. An over-narrow attentional beam is considered to be a critical component of this 'my world' existence.

An early memory: I am sitting on the floor in the nursery. In front of me is a toy, a kind of board with oblong bits of wood in various colours. There are holes in the board and the wooden pieces have to be banged in with a mallet that goes with it. I bang the blocks in and am aware of nothing but what I am doing. I am sitting facing the wall and there is nothing beyond what I am doing. No world. Only me and what I'm doing. I wish there were more blocks so that I could go on



banging down new ones instead of having to pick up the old ones. Before the blocks drop out, they slide down a curved track. I love that curve. I love seeing the blocks coming down that curve. Again and again. As long as I like.(Gerland, 1997, p.11)

This intense absorption is associated with descriptions of a lack of response to sound and to others attempts to engage their attention which in some cases led to queries of deafness. In addition Williams (1992) attributes her lack of awareness of pain and injury to the intensity of her absorption in her world at that time:

I also had hearing tests because, although I mimicked everything, it appeared that I was deaf. My parents would stand behind me and make sudden loud noises without so much as a blink in response. 'The world' was not getting in.  
(Williams, 1992, p.5)

Whatever the reason, I enjoyed twirling myself around or spinning coins or lids round and round and round. Intensely preoccupied with the movement of the spinning coin or lid, I saw nothing or heard nothing. People around me were transparent. And no sound intruded on my fixation. It was as if I were deaf. Even a sudden loud noise didn't startle me from my world.(Grandin & Scariano, 1986, pp.22-23)

I had not linked the tragedy of what she had seen with the pleasant, beautiful and hypnotic experiences of mere colour, sensation and sound, which had held me spellbound until I was about three and a half. I had been unaware of the pain of sores from unchanged nappies or my mother's neglect or brutality until I began to become aware of people's efforts at getting my attention.(Williams, 1992, p.115)

Authors describe their 'own world' experience in a number of ways. Gerland (1997) describes a sense of congruent timelessness, Jolliffe, Landsdown &



Robinson (1992) describes a sense of quietness or stillness which the 'real' world intruded on. Williams(1992) describes a more actively pleasurable contentment. All authors refer to a sense of security and safety in this self-absorbed world.

In this hypnotic state, I could grasp the depth of the simplest of things; everything was reduced to colours, rhythms and sensations. This state of mind held a comfort for me which I could find nowhere else to the same degree.

(Williams, 1992, p.60)

I spent a great deal of time inside myself, as if in my own world, screened off from everything else. But there was no world there inside me, nothing more than a kind of nothing layer, a neither-nor, a state of being hollow without being empty or filled without being full. It just was, in there, inside myself. This emptiness wasn't tormenting in itself. I was inside the emptiness and the emptiness was inside me-no more than that. It was nothing but a kind of extension of time-I was in that state and it just went on. But the sense of unreality and of always being wrong when I was out in the world, outside myself, was always harder to bear. I often sat in the garden looking at something, absorbed in a flower or a leaf. Then I felt neither wrong nor right. I just was, and that never stopped. I never suddenly wanted to do something else. Nothing was happening there inside me. I sat looking, observing.

(Gerland, 1997, pp. 19-20)

Gradually over the course of childhood authors describe a process of becoming more aware of a wider world through the intrusion of people and their demands. This is conceptualised as leading to a widening of the attentional beam away from a singular focus on an activity or event to include an awareness of people and a wider environment. Several authors describe early on a sense of jarring, irritation or anger at this intrusion into this absorbing world.

It was ages before I realised that people speaking might be demanding my attention. But I sometimes got annoyed once I realised that I was expected to attend to what other people were saying because my quietness was being disturbed. (Jolliffe, Landsdown & Robinson, 1992, p.14)

This widening of the attentional beam and awakening to the world of people is described as bringing with it a range of difficulties. Efficient attending to and making sense of this wider world is described as problematic. All but one of the authors describe vulnerability to sensory overload, hypersensitivities, and other sensory difficulties.

Then when I did realise that people were supposed to be more important than objects and became more generally aware, things began to take on a new and more difficult light. (Jolliffe, Landsdown & Robinson, 1992, p.16)

But when I was in the world of people, I was extremely sensitive to noises. Every summer we went to the family vacation place at Nantucket. This involved a forty-five minute trip on the ferry. I hated this part of the trip. What was exciting and adventuresome to Mother and my younger sisters and brother was a nightmare of sound to me, violating my ears and very soul. (Grandin & Scariano, 1986, p.23)

They describe a need to withdraw from overstimulation or 'painful' sensation by retreating for periods again into the safety of the 'my world' experience. This narrowing of the attentional focus is achieved in a variety of ways: focus on repetitive patterns, sounds or movement; focus on sensory detail, or engagement in a particular activity:

But ... there are times when things are so quiet and so placid, times when there is next to zero sensory stimuli, or times when they are so wrapped up in whatever activity they may be doing at the moment, that the fear fades. Just for a little bit.

(McKean, 1994, p.39)

My consolation, my safe retreat in the world, was a brown armchair in one corner. I could just fit in behind it. With my face close to the back of it, I would stare into the upholstery so that I could see every tiny little bit of it. I became absorbed in the brown material, in its threads, in the minute holes between the threads. Then the scratches on my soul would heal a little. I never turned to anyone for consolation. There was a self- consoling unit inside me, the only form of solace I knew, and that is where I went. I didn't know you were meant to get that from other people. (Gerland, 1997, p.16)

However, with age, greater understanding of what is considered socially appropriate and inappropriate, and motivation to overcome their difficulties a number of authors describe their efforts to avoid the temptation to retreat or succumb to the lure of their 'own world'.

As I had begun to be aware that something really did distinguish me from the others, it became even more painful to keep disappearing into myself. I kept feeling all the time that I was not living up to the expectations they all had of me. I felt I was disappointing other people, and I really tried to combat it.

(Gerland, 1997, p.123)

Seductively oblivion tapped upon the doors of my conscious mind, luring me inward, where it was restful. I would lie for a minute and several hours later climb back out of a spot in the wall in which I had been lost. I didn't want to take a nose-dive headlong back into 'my world'. I wanted to stay awake, aware, alert and alive.(Williams, 1994, p.91)

### **Two -wide beam**

Making sense of and responding to the world is described as effortful and problematic. A number of phenomena described by the authors are conceptualised as reflecting an overly-wide attentional beam which

contributes significantly to this difficulty. Authors describe an openness to all sensory stimulation which can become overwhelming, leading to a state of overload in which control and meaning evaporate. There is heightened distractibility which interferes with concentration to thought or activity. There is difficulty in 'foregrounding' any one aspect of this cacophony from 'background' stimulation. This experience is described as one of confusion, exhaustion, fear and panic.

Terminology such as 'overload' and 'fragmentation' are used to describe an experience of the world in which in which incoming information is experienced as a confusing and overwhelming mass of stimulation. A number of authors describe an experience in which people and objects are perceived as sensory events only. They may be experienced as a disjointed mass of shape, colour or angles without coherence or wholeness. Other examples suggest an openness to the world in rich detail which floods awareness. Authors accounts suggest that vulnerability to distractibility, fragmentation or overload is increased in unfamiliar, sensorially busy environments, high cognitive or multi-task demand situations. Williams identifies emotional stress in particular as a frequent trigger for sensory overload. In response to these experiences authors cite a range of voluntary and involuntary coping strategies. These include escape to low stimulation environments, deliberate strategies to move towards a narrowing of the attentional beam described as temporary retreat into the 'my world' experience, self-injury to induce an over-riding sensation of pain, and under acute stress an involuntary 'shut down' or catatonic experience.

The following quotes illustrate a range of experiences which are considered typical of the 'overload' experiences described by the authors:

Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seem to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. (Jolliffe, Landsdown & Robinson, 1992, p.16)

I couldn't think why I wasn't allowed to be left in peace. The noise the children made was a torment to me and I couldn't shut it out. I heard what everyone said and saw what everyone was doing. It frightened me and wore me out. (Gerland, 1997, p.71)

You get what's known as a fragmentation and things y'know it gets really weird it's like being tuned to say 40 channels at once you just get this whole overload of sensory impressions, and, if you get this when you're 4 the result is total panic (Weekes, 1995).

A number of authors describe people as particularly problematic. They describe an increased tendency to experience overload in situations of social interaction which are difficult for them. Jolliffe, Landsdown & Robinson (1992) identify the complexity and unpredictability of people as stimuli as the problem, whereas Williams (1992) suggests that it is lack of control and unpredictability especially in the realm of emotional demands which contributes to this tendency:

Objects are frightening. Moving objects are harder to cope with because of the added complexity of movement. Moving objects which also make a noise are even harder to cope with because you have to try to take in the sight, movement and further added complexity of the noise. Human beings are the hardest of all to understand because not only do you have to cope with the problem of just seeing them, they move about when you are not expecting them to, they make varying noises and along with this, they place all different kinds of demands on you which are just impossible to understand. As soon as you begin to think you are grasping how one of them works, something happens to change all this. (Jolliffe, Landsdown & Robinson, 1992, p.16)

Everything over which I did not have complete control (that which occurred through the motivation of others) always took me by surprise, often either shocking or confusing me. It often felt like the effect one gets in a 3D movie where you duck and weave as everything seems to be coming at you. For me, life was a movie-theater and my only means of walking out was to close out anything else that was going to reach out and affect me, particularly touch or affection. Just like in a 3D cinema the things on the screen begin to invade your world. That which was only a picture comes to life. This was the frightening reality of moving within 'the world'; and, in comparison, mine held a lot more comfort. 'My world' may have been lonely but it was predictable and came with guarantees. (Williams, 1992, p.62)

But as a child, the "people world" was often too stimulating to my senses. Ordinary days with a change in schedule or unexpected events threw me into a frenzy, but Thanksgiving or Christmas was even worse. At those times our home bulged with relatives. The clamor of many voices, the different smells-perfume, cigars, damp wool caps or gloves, people moving about at different speeds, going in different directions, the constant noise and confusion, the constant touching, were overwhelming. (Grandin & Scariano, 1986, p.25)

Hyper-acute perception and problematic hyper-sensitivity to particular sensory events are described by a number of authors as both a cause of and a characteristic feature of sensory overload. Mc Kean (1994) suggests that sensitivity to fluorescent lighting contributes to sensory overload while in addition Williams (1994) describes hyperacute hearing and vision as part of the experience of overload:

Fluorescent lights bother me, and this has caused a few sensory overload problems at ASA board meetings. (McKean, 1994, p.66)

Shifting back and forth from one voice to the other, the pattern of speech changed continuously. It was too quick for me to keep up with any interpretation and it was getting out of sync. Mrs. Miller's patterns



were just registering when Mr. Miller began to take over. My hearing started to climb, as though someone had turned up my volume, pitch, and speed controls. I covered my ears and tried to get a rhythm to calm down.(Williams, 1994, p.106)

The emotional experience of overload is invariably described as negative and predominantly one of fear and panic. It is described as adding to a sense of isolation and difference:

Trying to keep everything the same reduces some of the terrible fear. Fear has dominated my life. Even when things are not directly frightening I tend to fear that something horrible might happen, because I cannot make sense of what I see. Life is bewildering, a confusing, interacting mass of people, events, places and things with no boundaries. Social life is hard because it does not seem to follow a set pattern.(Jolliffe, Landsdown & Robinson, 1992, p.16)

I gradually learnt the names of most of the children in my class, but in the playground I didn't recognise those same children. There were too many faces, merging with each other. They dissolved, their contours blurred and I couldn't keep them apart. I didn't know who was who. The breaks were the worst ordeals of all. Balls would come whistling by from nowhere. A thousand voices. Children running and jumping. It was all one great unpredictable muddle, and it hurt inside whenever I tried to sort out my impressions. I would retreat towards the school building and lean against the wall. I went into myself. Here as well, of course, other children caught the scent of my difference (Gerland, 1997, p.89)

The authors describe a number of coping strategies to deal with this experiences. These include voluntary strategies such as escaping to a less stimulating environment, self-injury, self-stimulation, retreat into 'own world' and an involuntary 'shut down' of the attentional system.



*escape to a zero or low stimulation situation*

My health class took a field trip to the science museum here in Columbus. We were warned that anyone who left the group would be paddled. I left the group. Not because I wanted to, but because the sensory overload demanded it. I wanted to stay with the group desperately, but I was simply unable to do so. I needed to find a place that was a little more quiet and less stimulating to calm down. Afterward, I rejoined the group on my own. I didn't think anyone even missed me. (McKean, 1994, p.68)

*self-induced pain experience*

Y' know if you get this when you're 4 you're going to run out on the street where the traffic is. You're going to run full tilt at a brick wall. You're going to do anything to stop the sensory overload happening, because I'd much rather have pain um y'know pain is a violently overriding sensation rather than getting a whole lot of different confused jumbles - when you're an adult it's freaky enough but when you're a kid it's really bad

*'self-stimulatory' behaviours*

if your senses start to become pregnant or if you start to feel that reality's slipping away from you er you want to focus on something. You know sometimes they don't focus exclusively on pain like smashing into a brick wall - sometimes it will be just as easy to flick a light on an off very rapidly in the manner of the strobe light and you just focus on that I know like disco music you know you see a lot of people spaced out really wound up listening to the music and the autistic will be really cool sitting in the middle of the whole thing just watching the lights y'know it really coheres.

*retreat into 'own world'*

All this was also made more difficult by the constant murmur created by hundreds of pupils in an old stone building with high ceilings. This murmur was torment to me, as if eating into my mind, as if penetrating between my thoughts and making them dusty and hairy.

My thoughts grew ragged at the edges, and I couldn't dismiss the sound if it lasted too long. Trying to block it out was usually too much of an effort. All that was left to me was to let go and switch off the whole system. To retreat inside myself. (Gerland, 1997, pp.148-149)

*shut down/catatonia*

In particularly overwhelming situations a number of authors describe an involuntary 'shut down' or catatonic-type experience. The experiences of shut down which authors describe suggest a state of sensory immobilisation, where the sense modalities no longer operate in conjunction with the mind. Again there is variation in the severity of what is described.

If I get a lot of sensory overload then I just shut down - I literally shut down I become catatonic (Weeeks, 1995).

The perceptual problems of deafness, dumbness and blindness are experienced as very real. They are nevertheless caused by shutdown caused by extreme stress, brought on by an inability to cope with incoming information - often to do with emotions. (Williams, 1992, p.181)

But as the teacher was talking, a monotonous heaving ocean would well up in my ears, a sea with surging waves of rustling and coughing. It would make me slowly sink into myself and stay there. That inner emptiness was perhaps not all that unlike meditation, but with the great difference that I usually did not control the state myself.[] It just happened: my mains supply slumped to zero, then switched off, disconnected. (Gerland, 1997, pp.122-123)

Gerland (1997) describes a sense of extreme disconnection between peripheral and central processing of information under shutdown. This may have parallels with what participants in the interview study described as 'hearing but not registering'. However, even in a state of shutdown access to visual information remained her most reliable source of meaning:

My inner fuse-box was overloaded and the mains switch was now off. My senses did indeed remain in operation-I saw, I heard and I felt, but I no longer took anything in. My hearing was still there rattling away in my ear, but it didn't get through to me, nor could I fetch it. My sight sat on my retina as clearly as anything. As this was my sharpest, most reliable and most easily manipulated sense, I could actually choose to take in a little bit of it, but the rest I left there behind my eye. What I could see always penetrated most easily, even when the plug had been pulled on the system. What I felt, on the other hand, was simply outside my body, and if I had itched somewhere, in a way I would have known, but I would have had no reason to go there and fetch the itch so it didn't affect me.(Gerland, 1997, p. 178)

In addition Williams (1994) describes a tendency to disassociate 'experiencing without feeling' as having developed from her earliest years as a way of protecting herself from the stimulation and demands of her 'the world' experience.

I could drive past a row of trees and focus sharply upon one leaf of each tree, down to the detail of the contrast in the width of each vein. That was the way it was on automatic pilot. Like a handful of other autistic people, I could drive, paint, compose, and speak several foreign languages, all without thought or effort, but while I did I would be tuned out and everything that happened or was taken in the course of these actions came in without being filtered. It was like having a brain with no sieve but the consequences of my 'success' and 'high functioning' were shutdown, overload, dissociation, and losing time. It gave me a headache when my senses got flooded like this; it was like watching a cartoon in fast motion. (Williams, 1994, p. 42)

Williams (1994) describes learning to 'survive' sensory overload and recovery from 'shutdown mode' as an adult. She highlights the important role of others around her in helping or hindering these efforts, and in particular the importance of being given time and space to recover:

Meaning entirely fell out of all things visual. I didn't know what the visual image of the form next to me, which a few seconds ago had been my publisher, meant anymore. I looked desperately at this image trying to get the meaning back. All I knew was that the image was meant to be familiar. I found the name for the image. The name had no meaning. It told me nothing of its significance or relationship to me. All I knew was that it had to stay there and not move. I was blind and even this bit of meaningless familiarity was better than none at all. I looked at the flat, cold surface next to me and tapped it 'Window,' I said, naming it, trying to get the words to connect again. Chink, chink, said the cold, flat surface, and the word fell from my mouth with no connection between the two except my stubborn, insistent belief that the two were meant to connect. The empty word fell on my own deaf ears and I cried. I felt totally helpless to get my brain to reconnect. ... 'Lights,' I said, looking through the window of the shop, making a connection. I turned away. I felt the muscles tensing in my neck. It was like I had eaten a bag of lemons. I winced. 'We'll walk,' I ordered, suddenly surprised I had found a phrase. Great, I was coming back. ... I was so totally ashamed. I felt like I had wet myself in public. I felt so disgusted in myself, so let down. Yet I looked at my publisher and named her. I felt I could trust her. She hadn't freaked out. She hadn't run about like a mad hen. She hadn't gone into verbal blah-blah-blah, making overload worse or forcing dissociation. She hadn't slapped me, trying to make me 'come back'. She just stood there waiting for me. (Williams, 1994, pp172-173)

In adulthood when control and meaning-making are more refined, Gerland (1997) describes a positive side to the tendency to hear everything and see everything at once. This facility is similar to that described by Participant G in Study 2. Although the process is exhausting for her, she describes an advantage to her work in childcare arising from this propensity:

Even though it demanded so much energy of me, hearing everything and being unable to shut out sounds had its uses at the nursery. In a

room where there were many children playing in different groups, I knew what everyone was doing even when I was occupied with only one. Nothing escaped me, I could hear conflict as it arose and intervene at once (Gerland, 1997, pp. 215-216).

Similarly Williams (1994) recalls how her own experiences with overload and the strategies which she developed to deal with it proved helpful in her adult understanding of and interactions with children with autism:

The worker who had hired me was watching. She asked me about what I had done. I explained that I did what I myself would have needed. Grinding my teeth kept disturbing, unpredictable' and meaningless outside noise from coming in. Singing a repetitive tune and humming continuously did the same. The tapping gave a continuous rhythm and stopped the unpatterned movement of others from invading. I had simply replaced all these things for her so that she was freed up to do the next things down the scale of what she needed or wanted to do.

(Williams, 1994, pp 29-30)

### **Effortful Interpretative Attending**

The process of selectively attending to sensory events in order to efficiently make sense of and respond to them is described as problematic and energy sapping. Authors describe a range of difficulties including effortfully screening out background cacophony in order to attend to just one event, delay in hearing and responding to sound and difficulty in making sense of complex and dynamic stimuli which suggests a lack of automatic adjustment of the attentional beam. A range of factors are identified as adversely affecting the authors ability to attend to events for meaning: stress and anxiety, energy levels, multiple or complex task demands, sensorially busy environments, familiarity and also participants interest and motivation.

I kept trying to hold up a wall in my head between listening and everything around me so that the two shouldn't get mixed. Every sudden sound meant risking losing hold of the wall. With one 'hand' I held the wall up between the sounds, and with the other I tried to clean out my ear so that no new rubbishy sounds got in the way of what I was trying to listen to. With my third 'hand', the one I almost didn't have, I tried at the same time to sort out the information, the content of what I was listening to. This required total concentration, but no one could see what an effort it was. The fact that on certain occasions I was actually able to listen seemed to emphasise the adults' theory that it was only laziness and disinclination on my part that made me often hear nothing at all. 'You can if you really want to. 'Want to? I couldn't find any more 'want to' in me than I was already making use of. I didn't know what they meant. What did they really want of me? I lived on the very edge of what I could cope with, what I could endure. Why did they keep burdening me with more?(Gerland, 1997, p.95)

Anything I took in had to be deciphered as though it had to pass through some sort of complicated checkpoint procedure: Sometimes people would have to repeat a particular sentence several times for me as I would hear it in bits and the way in which my mind had segmented their sentence into words left me with a strange and sometimes unintelligible message. It was a bit like when someone plays around with the volume switch on the TV.(Williams, 1992, p.61)

Gerland (1997) vividly describes the tiring battle of trying to attend to multiple tasks in a noisy sensory environment:

I couldn't keep all these bits in my head, and if I asked, the teacher said I hadn't been listening properly. She had no doubt of it. At first I often came to a halt in the middle of something and didn't know what I was doing. The noise of the sewing-machines went right into me, too, vrrr, vrrr, clackety-clackety-clack, vrrr, vrrr. The sound didn't make me lose my foothold as other sounds did, but I simply couldn't shut it out. It



was louder than I could have imagined and it exhausted me, as if it were a battle between me and the noise, in which I tried to hold out my arms and push it away from me with the palms of my hands. It pressed in on me all the time- vrrrr, clackety-clack- vibrating and pushing against my outstretched hands. As soon as my arms tired and sagged a bit, the sound took over the whole of me. All the time, I had actively to keep it away from me, at the same time setting up a boundary, a kind of inner barrier, between the part of my mind devoting itself to shutting out the noise and the part that had to concentrate on cutting the piece of cloth I was holding. And I had to keep guard on the boundary there. If one side leaked over into the other, I was utterly lost. So what with these four simultaneous tasks, I hadn't all that much energy left. If another sewing- machine then started up- another sound to fend off- keeping that sound out was another separate activity, until I had added it to the sound of the first sewing- machine and made it into a single one. Not until then could I use one and the same force to keep both sounds out. But my energy ran out, and I couldn't do it. I hadn't enough 'inner hands' to resist it all (Gerland, 1997, pp.177-178)

Jolliffe, Landsdown & Robinson (1992) describes a difficulty in efficiently interpreting the different elements of a complex stimulus at once. Her description suggests a fragmentation in the way stimuli are perceived and a lack of automatic integration of information from the senses into a coherent whole:

Objects are frightening. Moving objects are harder to cope with because of the added complexity of movement. Moving objects which also make a noise are even harder to cope with because you have to try to take in the sight, movement and further added complexity of the noise. Human beings are the hardest of all to understand because not only do you have to cope with the problem of just seeing them, they move about when you are not expecting them to, they make varying noises and along with this, they place all different kinds of demands on you which are just impossible to understand. As soon as you begin



to think you are grasping how one of them works, something happens to change all this.

(Jolliffe, Landsdown & Robinson, 1992, p.16)

Jolliffe, Landsdown & Robinson (1992) also describes a delay in orienting or switching attention when spoken to:

When someone starts to speak to me, I have nearly always lost the first few words before I realise that I am actually being spoken to. This happens so much I have called them the 'waking up words'.(Jolliffe, Landsdown & Robinson, 1992, p.17)

Grandin & Scariano (1986) suggests that selective attending to events within the same modality may be particularly problematic:

Today, even as an adult while waiting in a busy airport, I find I can block out all the outside stimuli and read, but I still find it nearly impossible to screen out the airport background noise and converse on the phone. So it is with autistic children.(Grandin & Scariano, 1986, p.24)

Williams (1992) highlights the effect of stress on her capacity to make sense of others speech:

Similarly my response to what people said to me would often be delayed as my mind had to take time to sort out what they had said. The more stress I was under, the worse it became.(Williams, 1992, p.61)

Williams (1994) also describes the effect of new and unfamiliar environments:

I reminded myself there was no threat. I was busy taking in the contents of the room. The window, the blinds, the view outside, the number of floors in the building I could see through the window, the surface and color of the walls, the position of the seats, the marks on the floor, the surface of the table, and, of course, the placement of the

door. Dr. Marek spoke. It was hard to grasp what he said. I was too busy adjusting - to the new surroundings and new person, both at once, and to the feeling of being observed, as well.(Williams, 1994, p.37)

Because attending for meaning is effortful a number of authors describe variability in their capacity to hear from day to day depending on energy levels:

Some sounds around me I hardly reacted to at all. And there were others, louder ones, that I never even heard, or never seemed to hear- perhaps they were slopping about somehow in my ear without actually going inside. I hadn't the energy to sit there keeping guard over my ear all the time, to catch any possible sounds. When I did happen to have a scrap of energy left, then I was able to catch even the sounds that tended to stop half-way and carry me with them to my brain for further investigation. The result was that what I heard one day, I perhaps didn't hear the next.(Gerland, 1997, p.31)

Because of this variability and their inability to communicate their experience to others a number of authors describe how this led to others misunderstanding them:

There were climbing-frames in the playground, one of them red and blue and shaped like an igloo with a hole in the top. I liked it very much, and always wanted to climb on it. But that was impossible, because the presence of all the other children created such turmoil that I couldn't concentrate on climbing. I couldn't take the risk of climbing up something, then half-way up suddenly losing all sense of direction and balance. Carrying out anything to do with movement required my total presence of mind, my total control. Adults, of course, couldn't make out why one day I could climb up something, alone, and another day, with others there, I couldn't climb at all. They couldn't see the difference. It could only be due to reluctance, defiance, laziness or at best

shyness. Somehow I knew the difference between when I could and when I couldn't, but inside me there were few words with which to explain it. And the words I did have were hard to get out. (Gerland, 1997, p.76)

A number of authors describe factors which they found supported or facilitated their ability to attend to events around them. Gerland (1997) describes activity as helping to keep her from 'disappearing'. Jolliffe, Landsdown & Robinson (1992) finds music calming and therefore making her mind more receptive, while Williams describes strategies to reduce distraction by extraneous stimulation as helpful:

At junior school, the teacher had let me sit and draw on rough paper during lessons, and this had helped me stop sinking into myself. With paper and pen, I could keep my nervous system awake. True, I hadn't listened any more attentively to the lessons, had concentrated more on what I was drawing, but this hadn't mattered because I already knew what was being taught. ... Now that I was no longer given any rough paper, I started drawing on my desk. This was strictly forbidden, but I had got so used to having the paper that I was scarcely aware that I was drawing on the desk. It kept me in the here and now, in the room, so that I heard when the teacher addressed me. If on account of some activity or incident I couldn't keep myself present, if I sank into myself, then I never heard if anyone spoke to me. And it was important to answer when spoken to, I knew that. Not answering seemed to be what provoked them most of all. So I tried to remain present-I drew on the desk, was reprimanded, tried to stop drawing on the desk, sank into myself, didn't answer when spoken to, was reprimanded, tried to be present, started drawing on the desk again, and so on. (Gerland, 1997, Pp. 122-123)

There is something very special about music. It can be calming when all else fails and it seems to make the mind open up and become more receptive. (Jolliffe, Landsdown & Robinson, 1992, p.17)

'Speak to me through my words,' I asked Dr. Marek. I wanted to cut down the struggle in putting mental pictures to words. 'Can you take the dancing out of your voice [intonation] and not pull faces [facial expression] so you don't distract me from what you're saying?'

Perhaps the request was unreasonable but I felt it was worth the cost. I told him to speak evenly and tried to listen with meaning more than ever before in my life. (Williams, 1994, p. 96)

Computers. These are a god-send to the autistic population. Especially the field of telecommunications. Public message bases and private mail are easier for me to communicate with because I don't have to use all that energy trying to talk in a normal manner. I can just type in silence. This cuts down drastically on sensory overload.(McKean, 1994, p.49)

Williams(1992;1994) suggests that dissociation, operating on automatic pilot without an experiencing self, protected her from the worst effects of living with 'a mind with no sieve'. However, with age and insight this proved a less than satisfactory compromise:

Though the feeling which precipitated my 'losing myself' happened most often, beyond my control, I found I could either give in to it or try to fight it. It was hypnotic, and I often found myself giving in to it and sometimes sought the feeling when it wasn't there. It was as though I was hooked on this state of being.(Williams, 1992, p.40)

For so long this tentative balance of denial had been the best compromise I had found. But the price tag was too high; to merely function was no longer such a good exchange for 'to live'. The choice was not an easy one though. I had to accept the harsh reality that to live would involve being so much less than I could seem and be so much more difficult than sleep-walking. Everything was too colorful, too invasive, too constantly changing. I could switch off emotion and self, it would be tolerable; a film of someone else's life with my body

cast in the leading role. I could hold onto self and emotion and awareness and overload under the weight of everything coming into a mind with no sieve. (Williams, 1994, p.43)

## **Appendix 13**

This appendix relates to Chapter 7, Study 5. It contains a shortened and jargon -free summary of the findings of Study 2, sent to respondents for the purposes of Respondent/ Cohort Validation.

## Study 5

### Summary of Analysis for Respondent/Cohort Validation

#### Background

I am a Clinical Psychologist and I have worked with people with autism for nearly 15 years. I first became interested in unusual sensory-perceptual experiences in autism as a result of listening to Temple Grandin talk at an International Conference in The Hague, Netherlands in 1992. Temple described a number of sensory-perceptual problems and made a plea for clinicians and researchers to pay more attention to these types of experiences in the lives of people with autism.. Much of what Temple described seemed to fit with my own experience of working with less able, non-verbal people with autism and offered a possible way of understanding some of their behaviour which up until that time had puzzled me. However at that time there I found that there was very little written in clinical psychology books and journals on autism which helped me to learn more about these sensory-perceptual experiences.

When some years later I got the opportunity to do research towards a Doctoral degree I decided to investigate this area. I was interested in finding out more about the types of sensory experiences people with autism had, about the impact of these experiences on their lives, and how they made sense of them. As part of this investigation I interviewed six people with High-functioning Autism/ Asperger's Syndrome about their experiences. I analyzed transcripts of these interviews using a qualitative research approach. This approach has the aim of producing theoretical understanding which is developed from and grounded in the words and experiences of participants rather than from a perspective of already existing theory.

What follows is a short summary of the types of experiences participants in my study reported. This is followed by my own analysis or 'theory' as to what processes may explain these experiences. I would be extremely grateful



for your views and feedback on my analysis and to what extent you feel it is helpful in understanding sensory-perceptual experience in autism.

### **Summary of types of sensory-perceptual experiences described**

Participants described a broad range of experiences across the sensory modalities that were both problematic and pleasurable. These experiences were described as primarily happening in childhood but some do continue in milder form into adult life. There was a lot of variation between participants in the range of experiences they reported and in the impact of these experiences on their lives. For example, some participants described problematic reactions in only one (e.g. sound) or two modalities (e.g. sound and touch), whereas others reported problems across all sense modalities (e.g. sound, vision, touch, taste, smell and internal body state). The range of experiences included exceptionally good sensory perception (hyper-acuity), under- and over-reactivity to stimuli, sensory distortion, blurring or overload, heightened distractibility and sensory fascinations. These are outlined in a little more detail under the major sense headings: sound, vision, touch, taste, smell and internal body states.

#### **Sound**

- In the absence of effortful concentration an experience of sound as distorted, blurred, confused
- Difficulty in maintaining attention to a task because of distraction or interference by sounds in the environment or internal thoughts. This included difficulties in screening out background sound
- Failure to hear, or delay in 'registering' or 'waking up' to sound associated with a state of intense absorption in thought or activity
- A need to deliberately or effortfully focus on sound in order to make sense of it
- In certain circumstances deliberate blocking out of sound using a range of strategies including physical blocking (e.g. hands over ears), or focusing on one repetitive sound or activity.

- Hyper-acute hearing: hearing at lower volume, at greater distance or a greater range of sound frequency than others or hyper-acuity for specific sounds (e.g. sounds of particular interest to the individual)
- Problematic hypersensitivity such as distress in response to loud, high pitched sound or unexpected sound or specific types of sound such as certain voices, electrical equipment or vehicle noises
- Experience of certain sounds as echoing or reverberating. This may intensify the impact of unpleasant sounds or drown out other sound
- Fascination with and pleasure in certain sounds especially repetitive, predictable or soft sounds

### **Vision**

- Visual distortion and blurring as part of a wider sensory confusion in certain circumstances
- Being prone to distraction by the events in the wider visual environment especially by repetitive or dynamic pattern or events within peripheral vision.
- A tendency towards 'entrapment' by stimuli which have a high degree of repetition, predictability or dynamic pattern. This results in a state of absorption akin to intense daydreaming. In this state 'interruptions by others may be perceived as jarring or aversive. Disengaging from these stimuli requires effort and vigilance.
- A sense of discord or irritation where disruption of repetition, pattern or symmetry occurs within the visual environment. This discord may disrupt or interfere with participants attending to other events within the environment
- Hypersensitivity to specific stimuli such as bright light or colour being perceived as over-intense
- A preference for the familiar, and a difficulty in accepting change within familiar visual environments
- Difficulties in judging distance and size

### **Touch**

- Unpleasant sensitivity to particular fabrics or materials and certain body-care activities such as having hair cut
- Dislike of specific food textures or combinations

- Unpleasant experience of affectionate touch and other forms of social touch
- Pleasure and comfort in specific tactile fascinations or experiences such as the feel of particular fabrics or the experience of being encased in blankets or water

#### **Internal body states**

- Under-and/or over-reactivity to pain experience and illness
- Under -reactivity to temperature, hunger and / or thirst
- Problems in inhibiting the impulse to eat or drink

#### **Taste**

- Strong preferences for, or insistence on, familiar foods and tastes which may include insistence on having a particular food item at every meal e.g. grapes with everything
- Avoidance of new or unfamiliar foods or tastes

#### **Smell**

- Hypersensitivity to certain smells i.e. experienced as over-intense or overwhelming
- General under-reactivity to smell

### **Analysis**

I see the central theme running through participants descriptions of their sensory experience, (pleasant and unpleasant) as that of disordered attention. I think of the attentional system as being disordered in several key aspects: (1) an impaired 'attentional beam' that, without effortful management, moves erratically between a state of over-narrow and a state of over-wide focus (2) a bias to repetition and sameness in the attentional system that makes it more likely that attention will stay with whatever is currently being attended to rather than shift to a new focus. This results in a lack of flexibility in switching attention and also gives precedence or priority to specific stimulus

characteristics (3) an attentional orientation to the sensory world. This is a sensory-based experience, with little reference to the social world, that is associated with a non-reflective, 'in the moment' experience and a concrete, physical world view. (4) perceptual hyper-sensitivity which leads to exceptional capacity to detect, or excessive reactivity to, particular types of sensory events in one or more modalities.

I see the working of this disordered attentional system as subject to a number of influences. The emotional state of the person is one key factor that affects the working of the system. However, developmental factors such as age, memory and learning are also identified. With increasing age, maturation and learning the system becomes more reliable. Because the attentional system is impaired participants may experience a feeling of lack of control and mastery over basic perceptual processes. This problem improves with age.

### **Impaired attentional beam**

We can think of the way that we direct our attention to events around us as being like a beam or a spotlight. This beam automatically narrows and widens in order that we can, without effort, make sense of, and respond to, events around us. I felt that the idea of an attention beam that is inefficient was a useful way of understanding some of the sensory-perceptual experiences reported by participants. I made sense of these experiences in terms of a beam which did not work well automatically but instead required effort from participants. Without effort this beam could either become too narrow or too wide.

When the beam is too narrow participants are intensely absorbed in one event or activity resulting in a diminished awareness of events outside of the object of focus.

This could include internal as well as external sensation. Because of this intense focus, participants are much less responsive to, and distracted by, the wider environment or even sensation or messages from their own bodies. When this happened participants might not be aware of other things that were going on around them. For example, they might not hear sounds such

as things that were said to them or they might be unaware of bodily temperature such as feeling cold.

On the other hand the attention beam could sometimes be too wide, where participants are aware of and distracted by too many sensory events and unable to selectively attend to just one. This results in a kind of sensory overload and the inability to screen out background stimulation. In this state, noisy or busy situations or places that contain highly distracting or particularly intense features are especially difficult to deal with.

Because automatic narrowing and widening of the beam is problematic participants have to work at not getting stuck at either of these two extremes. As a result, following and making sense of events around them requires active effort and concentration. A

number of participants explicitly and repeatedly referred to this need for active listening or deliberate and effortful concentration in order to make sense of the environment. They referred to the strain or effort involved in seeing or listening to events around them or needing to deliberately 'disengage' from particular events. A number of participants particularly highlighted difficulties in following the speech of other people.

My understanding of what participants describe is that the working of the attentional beam does become more automatic and efficient with age and learning. Nevertheless the ability to selectively attend seems to remain vulnerable to inefficiency and distraction. A number of factors were identified by participants as contributing to this inefficiency. These included the intensity and/or busyness of the sensory environment, the need to sustain attention or concentration over time, the difficulty of the task they had to do and being distracted by stimuli which have a particular appeal or relevance to the person.

In addition the emotional state of the person also seemed to affect the efficiency of the automatic working of the attentional beam. In a relaxed state automatic narrowing and widening of the attentional lens seemed to be more

efficient and less effortful. Emotions such as anxiety and fear led to a less reliable system with increased difficulty in efficient selective attending.

As a result under certain conditions, participants sometimes seemed to deliberately move towards a state of over-narrow focus so they could switch off distracting background events. This was achieved through a variety of strategies including deliberately focusing on one sound or activity (e.g. repetitive humming, spinning a top), physically blocking out sound (e.g. fingers in ears) or cognitive strategies to switch off background sensory events. In addition a number of participants do seem to acquire a degree of voluntary control over the attentional beam which allows them to very effectively and deliberately screen out particular sensations (such as pain) from attentional awareness.

### **A bias to repetition and sameness**

In addition to the idea of a problem with the attentional beam, I understood other aspects of what participants described in terms of a second idea: that of a deeply ingrained bias to repetition and sameness. I see this bias as being made up of two linked tendencies: a tendency for events that are already within awareness to repeat or 'stick,' and a sort of inbuilt 'pre-wiring' within the attentional system to attend to events that are repetitive and predictable. Together, as I see it, these make it difficult for participants to switch attention quickly and flexibly from one event to the next and to follow the flow of events around them.

Participants described certain unpleasant sounds and visual events as repeating or echoing in their mind, adding to their unpleasantness, before gradually dying away. In the case of sound this may also temporarily interfere with the ability to hear other 'new' sounds. Participants also describe thoughts as 'sticking' and a difficulty in making way for new thoughts. Again this adds to the impact of unpleasant or distracting thoughts because they cannot easily dismiss them from their mind.



Participants describe their attention as being drawn to sensory events that are repetitive and predictable, for example patterns and symmetry in the visual environment. Some participants say they find it particularly difficult to stop paying attention to these sorts of stimuli. Sensory events that are repetitive and predictable may also be a source of fascination. These events are often associated with a sense of contentment or pleasure. Similarly, if these characteristics are disrupted or broken participants may feel anxious or irritated as a result.

I see this bias as also being reflected in descriptions of repetitive play behaviour and stereotypes. Participants describe these behaviours as often happening 'automatically,' without their being aware that they are doing it. They describe having to actively stop themselves engaging in these behaviours in order not to appear odd. These behaviours are more likely to occur if they are anxious or excited. However, some participants say that these behaviours then gradually help them to calm down.

Participants describe this tendency to repetition and bias as gradually getting less as they get older. This is because they are more motivated to overcome it and/or because stopping it becomes more automatic with practice. In this respect, participants acquire more control over their attention and behavior as they get older.

My understanding of what participants describe is that this bias to repetition and sameness in attention is part of a wider preference for sameness and dislike of change that affects all aspects of their lives. This broader preference affects general sensory preferences like taste and diet and choice of clothing. However, this also becomes somewhat less of a problem as participants get older.

### **A sensory world**



A third idea which I found helpful in understanding what participants described is the notion of an attentional orientation to the sensory world. This is a sensory-based experience that leads to a non-reflective, concrete view of the world.

I think of this as an experience in which participants awareness of what is happening is primarily rooted in the physical and sensory aspects of the world. There is little reference to the social world of people, and the shared meaning and social understanding which goes along with this. A number of participants very explicitly describe a childhood awareness which centered on aspects of the sensory-perceptual environment. They describe intense interest, curiosity and excitement in the details of the physical environment. These dominated their awareness, and they describe a co-existing lack of interest in or awareness of people.

This sensory world is described as a significant source of emotional experience.

Participants describe themselves as getting pleasure from and being fascinated by

sensory events such as repetitive sounds, tactile sensations, patterns within the visual field or the sensory feedback arising from repetitive or stereotypic behaviour. Strong emotional responses such as a sense of loss or anger are described in response to interruptions of, or intrusions into, these pleasant sensory experiences. I see descriptions such as these as reflecting immersion in a physical, sensory world which does not have people at it's core.

My understanding of what participants describe is that an important aspect of this type of experience of the world is what I call 'in the moment awareness': a consciousness which is based in the present moment and in which there is little search for meaning, explanation or connection other than at the level of association. 'In the moment awareness' is explicitly described by one participant but I see it as implicit in the accounts of others. This grounding of awareness in the present amplifies both positive and negative experiences of sensory events, since at that moment the present is all there is: 'the only thing in existence'. I also see it as contributing to a naive sense of

wonder about the world and to largely associational understandings (and misunderstandings ) of connections between events. These associations in turn impact on the emotional value of particular sensory events or situations. For example, sounds or smell associated with positive emotional experiences themselves become perceived as pleasant, and those associated with unpleasant events come to be judged as unpleasant or aversive. Objects or activities associated with situations in which participants have felt safety or comfort may be sought out as a way of recreating this experience in anxiety provoking situations.

Because the sensory and physical aspects of a situation predominate, and because participants do not have easy access to shared social learning about the world, this leads, as I see it, to an over literal way of interpreting and responding to the world. Examples of this 'physical world view' described by participants include interpretation and response to thoughts as 'real' sounds, the literal interpretation of distant visual objects as 'small' and reliance on physical (e.g. hands over ears) as opposed to social strategies for dealing with unwanted demands or events.

I view a number of the experiences described by participants as clearly reflecting the underlying social impairment in autism: a problem in understanding people, and emotion in particular. Participants describe difficulties in understanding their own and others' emotions when being held or hugged. This leads to feelings such as losing control or being overwhelmed. Because the emotional meaning of these interactions is confusing, the physical or sensory aspects of the situation may take on greater importance for participants, and these in themselves may be experienced as unpleasant. An example of this would be a heightened awareness of body odour or perfume when being hugged. In addition, because social routes to feelings of comfort and security are reduced, as I see it, participants may seek out these experiences through non-social sensory means, for example seeking out alternative sources of deep pressure touch which others might get from being held or cuddled. A number of participants suggest an orientation to the physical world because it is less problematic than the social world. For example difficulties with eye contact

are described as leading to visual gaze being directed at the physical environment. One participant describes a preference for interacting with objects because 'getting it right' with people is difficult.

As they get older a number of participants describe a developing realisation that this lack of sociability is different from the way others experience the world. As I see it this represents a move away from the immediate sensory world to a more socially aware, reflective experience. In turn greater reflection and social awareness contributes to a lessening, with age, in both problematic sensory experience and pleasure in sensory events. Participants also describe how increased motivation to 'fit in' leads them to manage and respond to sensory events in more socially acceptable ways. Participants also indicate that social behaviours such as shaking hands may become less problematic with age.

### **Hypersensitivity**

The notion of hypersensitivity refers to 'exceptional' or 'hyper-acute' perception. I believe that this idea is necessary to account for a number of the experiences that are described by participants. Participants describe this type of perception in different ways. It may be reported in only one modality or in more than one modality. It may be limited to very specific sensory events or it may be a more general characteristic of perception within a particular modality. I see this hyper-acuity as being reflected in participants accounts in two ways: what might be understood as an 'amplified volume' experience and secondly the experience of perceiving events outside of the normal perceptual range. I think of 'amplified volume' as underlying participants descriptions of hearing at greater distance or at lower volume than others, of a general intolerance of loud sound because it seems 'too loud', of 'subliminal' hearing, and the over-intense experience of brightness in the visual environment. The second is reported by one participant only. He describes a capacity to hear sound outside of the normal frequency range as contributing to an aversive experience of shrill, high-pitched sound. Some participants describe themselves as hypersensitive to very specific stimuli

such as mechanical sound or particular smells such as perfume.

Hypersensitivity to these events can occur alongside under-reactivity to other events within that particular modality.

My analysis suggests that this hyper-sensitivity decreases with age and this is reflected in participant descriptions of a reduction in 'exceptional' sensory - perceptual abilities such as acute hearing as they get older. This in turn contributes to a lessening of unpleasant and aversive experiences which result from these hypersensitivities.

I am unclear from my analysis as to whether this hypersensitivity reflects 'organic' sensory -perceptual capacity (hard wiring) which is outside of the normal or typical range or whether it reflects a well-honed skill in the detection of a greater range (intensity, volume) of sensory events in an attentional system which is embedded in a sensory / physical world. I view participant accounts of an 'amplified volume' experience as suggestive of an 'organic' hypersensitivity. On the other hand, I see reports of hyper-acuity for particular events that have a special salience for the individual but at the same time under-reactivity to others, as supporting the notion that hypersensitivity may be the result of well-practiced detection of sensory events. Participant descriptions of decreasing hyper-sensitivity with age, as immersion in a sensory world lessens, would also tend to support this explanation.

### **Disordered Attention: Impact and Change**

My view is that the sensory-perceptual experiences described by participants can be understood in terms of an attentional system that is characterised by the four key elements described above. A consequence of this attention system is that participants experience to differing degrees a lack of reliable control over basic sensory-perceptual processes. This lack of full control may be judged by participants in different ways. It may be judged as problematic, and for example, lead to anxiety in certain situations. In other situations a participant may experience this lack of full control as a source of positive

skill, for example for one participant the ability to 'hear' conversation without awareness at the time. Alternatively there may be a more emotionally neutral acceptance of the system.

I see the attention system as becoming more reliable over time. In addition to the developmental changes in key aspects of the system already described, my analysis suggests that a number of other processes also contribute to this outcome.

Memory is identified as affecting sensory-perceptual experience. One participant identified the ability to remember the order and sequence of events (reported to have developed late in middle childhood) as contributing to improvement in his ability to make sense of events around him. As I see it, this moves him away from a non-reflective sensory experience. Another participant found that anxiety about bodily symptoms reduced as his ability to recall previous experiences of minor illnesses improved.

A process of familiarisation and repeated exposure ('getting used to') problematic sounds, tastes and textures is also described by participants as contributing to a lessening of problematic reactions to specific sensory stimuli.

A number of participants suggest that learning better coping strategies has contributed to better management of sensory-perceptual difficulties. These include establishing routines around eating and drinking to compensate for lack of reliable awareness of or recognition of these internal sensations, or in the case of chronic muscle tension becoming aware of it and learning techniques to reduce this.

### **Your comments and feedback**

I am interested in your views on the extent to which the above analysis reflects your own history of sensory-perceptual experience. Your comments

on sensory-perceptual experiences among people with Autism/Asperger's Syndrome in general would also be welcome. I have attached a consent form for you to read and complete. I would be grateful if you could let me have your views within the next two weeks.

Thank you for your time and participation.

Meena O'Neill

## **Appendix 14**

This appendix relates to Chapter 7, Study 5. It contains a copy of letter to those who participated in Studies 2 and 3, inviting their comment on the findings of Study 2, for the purposes of Respondent Validation.



**Accompanying letter to parents and participants: Respondent Validation**

Carrowholly,  
Westport,  
Co. Mayo  
Rep. Of Ireland

Name  
Address

Dear X (Parents name),

My name is Meena O'Neill. You may remember that I visited you in (month/year) and that you kindly participated in an interview with me about X's (name of participant) sensory-perceptual experience. I agreed to contact you again when I had completed and analysed all my interviews.

I would like to apologise for the very long delay in getting back to you. Unfortunately my research was delayed due to ill-health. Then I moved back to Ireland just over a year ago and this further delayed things. However, I have now completed my analysis of what X and the other participants told me about their sensory-perceptual experiences, and, as agreed, I enclose a summary of what I found and how I made sense of it. A summary of what I learned from my interviews with yourselves and other parents will follow shortly.

I have also included a copy of my analysis for X, and would be grateful if you would pass this on to him. I would like to invite both yourselves and X to comment on my analysis. X may wish to comment on the extent to which he feels the main elements of my analysis accurately represents his history of sensory-perceptual experience. You may also wish to comment on this from your perspective or you may prefer to wait and comment when you've had the summary from the parent interviews. I hope to incorporate any feedback you or X may wish to provide into the final write-up of the study.

If either X or yourselves would like to provide feedback on my analysis I can be contacted at the above address. Alternatively you can contact me by e-mail at: xxx or by telephone at xxx ( I can ring you back). If having the analysis sent by e-mail would be more convenient for you, please let me know, with your e-mail address.

I hope that you and your family are well. Again, apologies for the very long delay in getting this summary to you and my sincere thanks for your participation in this research. A summary of my analysis of parent interviews should be with you before Christmas.

With very best wishes,

Meena O'Neill

## **Appendix 15**

This appendix relates to Chapter 7, Study 5. It contains a copy of the message posted on internet sites, inviting participation in Cohort Validation of the findings of Study 2.

**Message posted on Internet sites, Study 5**

**Message posted on Internet**

Title of the study: The phenomenology of sensory-perceptual experience in Autism and Asperger's Syndrome.

Name of Researcher: Meena O'Neill, (Chartered Clinical Psychologist and Postgraduate research student). Contact address: xxxx. Tel: xxxx. E-mail: xxxx.

I would like to invite people with a diagnosis of Autism or Asperger's Syndrome to contact me regarding some research that I'm carrying out into sensory-perceptual experience. As part of my research, I have completed six in-depth interviews with people with Autism/ Asperger's Syndrome about their sensory-perceptual experiences. I have produced a short report summarising my analysis of what they described. As a next step in the research process I believe it is important that I get feedback on my analysis from a wider group of people with Autism/ Asperger's Syndrome and that I take this feedback into account in my final report. If you are interested in volunteering to read and comment on my analysis please contact me by e-mail. I will then send you on a copy of my report for your comment and feedback.

All feedback will be treated confidentially and used only for the purpose of this study. Your anonymity will be guaranteed.

Meena O'Neill

e-mail: xxxx

## **Appendix 16**

This appendix relates to Chapter 7, Study 5. It contains a copy of the Consent Form completed by participants in the Cohort Validation study.

## **Cohort Validation: Study 5**

### **Consent Form**

#### **Purpose of study**

The purpose of this study is to invite comment from a wider group of people with Autism and Asperger's Syndrome (A/AS) on my analysis of sensory-perceptual experience in autism. This analysis was based on in-depth interviews with six participants with A/AS. Feedback and comment from the wider group will then be incorporated into a final report.

#### **Confidentiality and Anonymity**

The views and information you share with me will be treated in a confidential manner to ensure your anonymity. I will not disclose any personal details you provide or your e-mail address to anyone else. I hope in due course to publish the outcome to this research in an academic journal. Any views or quotes taken from your feedback will be reported anonymously. Your participation in this study is of course voluntary.

If you have any questions about the study please contact me with your queries.

If you have read the above information and are happy to participate by providing your comments and feedback on my analysis, please type in your name and the date in the spaces below and return this form to me at my e-mail address: xxxx

Type in your name/e-mail address here:

Type in the date here:

With thanks,  
Meena O'Neill

## **Appendix 17**

This appendix relates to Chapter 7, Study 5. It contains a copy of the letter sent to personal web site authors to invite participation in the Cohort Validation of the findings of Study 2.

## Invitation to web page authors

Dear X,

I came across your website while looking for first-hand accounts of Autism/Asperger's. You invite e-mail correspondence so I thought I would contact you to ask if you would be interested in providing comment and feedback on some research that I've been doing. I am inviting comment from people like yourself who have created World Wide Web home pages and who invite correspondence. I have also posted notices on autism e-mail lists. The following briefly describes who I am and the research that I'm doing.

Title of the study: The phenomenology of sensory-perceptual experience in Autism and Asperger's Syndrome.

Name of Researcher: Meena O'Neill, (Chartered Clinical Psychologist and Postgraduate research student). Contact address: xxxx. Tel: xxxx. E-mail: xxxx

Research supervisor: Dr. Robert Jones, (Senior Lecturer), School of Psychology, University of Wales, Bangor, UK. Tel: xxxx.

E-mail: xxxx

I would like to invite people with a diagnosis of Autism or Asperger's Syndrome to contact me regarding some research that I'm carrying out into sensory-perceptual experience. As part of my research, I have completed six in-depth interviews with people with Autism/Asperger's Syndrome about their

sensory-perceptual experiences. I have produced a short report summarising my analysis of what they described. As a next step in the research process I believe it is important that I get feedback on my analysis from a wider group of people with Autism/Asperger's Syndrome and that I take this feedback

into account in my final report. If you are interested in volunteering to read and comment on my analysis please contact me by e-mail. I will then send you on a copy of my report for your comment and feedback.



All feedback will be treated confidentially and used only for the purpose of this study. Your anonymity will be guaranteed.

If you are interested in providing your views on my analysis please read and return the Consent Form attached. I will then send you a copy of my analysis for your comment. If I do not hear from you, you will have no further correspondence from me.

Thank you for taking the time to read this message.

Meena O'Neill.

e-mail: xxxx

## **Appendix 18**

This appendix relates to Chapter 7, Study 5. It contains a copy of the letter sent to authors of published autobiographical accounts seeking their participation in the Respondent/Cohort Validation of the findings of Study 2.

**Letter to interested authors of autobiographical accounts**

Dear X,

My name is Meena O'Neill. You may not remember me, but I met you at the Glasgow Conference in Scotland in May. At the time you kindly agreed that I could e-mail you for your feedback on some research that I am doing into sensory-perceptual experience in Autism. If your kind offer is still open, then I would be most grateful for your comments and feedback on the attached summary of my research. The summary describes what I found out about sensory-perceptual experience when I talked with six people with Autism/ Asperger's Syndrome, and how I have made sense of it.

As a next step in the research process I believe it is important that I get feedback from people with Autism who are interested and willing to do so, and that I take account of their comments and feedback in my final report. Confidentiality will of course be respected.

Thank you for taking the time to read this message, and, I will greatly value any feedback you wish to provide.

Yours sincerely,

Meena O'Neill.

## **Appendix 19**

This appendix relates to Chapter 7, Study 5. It contains a detailed account, with illustrative verbatim data, of the analysis of respondent accounts in Chapter 7.

## Chapter 7

### Analysis of Feedback: Respondent Validation Study

#### Nature of feedback

The nature of the feedback I received varied from individual to individual. Most (five) respondents provided detailed report of their own sensory experiences together with more general comment on my analysis. One respondent provided a very detailed accounts of his own sensory-perceptual experience but with little overall general comment on my analysis. However, another respondent provided only an overall general comment on my report. The respondent who had taken part in the interview study responded with specific comments on aspects of my analysis and did not provide details of his own sensory-perceptual experience which were already known to the author. In addition one other respondent (published autobiographer) confined her comments to specific aspects of my analysis and contrasted these with her own theoretical position on the nature of the autistic condition.

#### Approach to analysis

My approach to analysis of the feedback received was as follows:

- (1) I read each respondents feedback individually noting points of affirmation, disagreement, and additional or augmentative observations with regard to each of the core elements of my analysis.
- (2) I noted more general comments on my analysis from each respondent, again noting areas of agreement, disagreement, additional or augmentative observations, cautions and other comments relevant to my analysis.
- (3) Feedback from respondents were then summarized together under the following category headings:

General Comments

Impaired Attentional Beam

Sensory-based World

Perseverative bias

Hyper-sensitivity

In presenting respondent's feedback a decision was made not to correct spelling mistakes or other errors. In addition respondents feedback is presented, with the exception of font style and size, in the written format in which it was received. These decisions were made in order to preserve the immediacy and feel of each respondents's feedback as in some cases the manner in which the feedback was written seemed to complement the particular contribution and personality of the respondent.

### **1. General comments**

This section deals with general comments about the research and observations about the analysis as a whole.

With some cautions and reservations which will be described later, those who expressed overall evaluative observations were positive in their comments:

R1: Wow! Interesting. Fabulous! You should write a book on the sensory-perceptual experiences of autism. This is something of major importance for people to know about. Fascinating! Let me begin my comments by saying that I am an autistic gentleman of 57 years of age. I find your analysis of the sensory-perceptual activities to be absolutely astounding. I may indeed be an ideal case in regards to your analysis. I have experienced about 95 percent of all the things that you have described in your report. ... I agree with most of your analysis.

R3: I don't know if it has been worth your while to read through all these words. In case you were not able to do so, I will say here at the end that I think you are on the right track.

R4: My initial reaction to what I've read (I haven't finished or thought about it yet) is that you're right on. I've been obsessed with [understanding] autism for over 3 years now and the attention shifting thing is something that always made so much sense to me. You put my thoughts and theories into words.

R6: So here are some of my reactions to your research.

I think your efforts are great  
in this frontier, the autistic nervous system.

In addition to positive observations about the content, the feedback also contained comments welcoming my research effort and expressing appreciation of the opportunity to provide feedback. One respondent noted how participation provided an opportunity to reflect and make sense of her experience in a way that was positive for her:

R3: Thank you for giving me (and other autistic) a chance to read about your work.

R6: I cannot exactly explain what is happening to me and so I welcome outside speculation like your own.

... Part of me doesn't want to tell you this because I am used to not connecting with the world.

I realize you won't understand a lot of what I have written.

But since this makes me stretch to understand myself for myself

I am captivated with the pictures you have brought to my head.

These e-mails from me are good for my well-being thus far.

However, two respondents took issue with the what they saw as negatively value laden terminology which devalued autistic experience in comparison to neurologically typical (NT) norms. In particular terms such as 'disordered', 'naive wonder' and 'literal' drew strong censure. These respondents provided strong argument for a more respectful language of difference (as opposed to that of dysfunction or deficit) that would serve to emphasise the positive strengths and contribution of their experience and view the world.

R8: When these items are taken into consideration and individuals 'walk carefully' beside us, take time to understand us and recognise the differences between us (neuro-typical/ autistic) then as autistic individuals living and relating in a mostly non-autistic world, we can



do very well. If folk only see our difference in the terms of disorder, dysfunction and so on, then they may fail to see the benefits of being singly minded, singly focused etc.

R6: And so at this point

I wonder about you stepping into this frontier  
with the old terms of literal thinking and naive wonder.

I am a thinker.

I do wonder.

But am I naive because I refuse to limit myself to NT cultural norms  
(another name for their repetitive behaviours and their insistence to surround

themselves with the same environment where ever they go)

and is my thinking literal because I refuse to  
evolve into an NT thinker only?

I prefer to think outside the NT box,

to consider all answers possibilities to the answers in this world.

I prefer to listen to my imagination.

Who knows it may be right.

The later respondent also highlights another potential limitation of the research endeavor and resulting analysis. For her and many other people with autism who 'think in pictures' there is real difficulty in translating the richness and fullness of their experience into the 'foreign language' of words. Conversely, by implication, the researcher may have the reverse difficulty and as a result may make false or 'culturally' unfair assumptions about the nature of the other's experience:

R6: I feel like I am trying to explain all of this in a foreign language.

I am very very picture oriented.

Using words to fit the pictures inside my head  
is like putting a square peg in a round hole.

Never assume you know what is going on in our head  
just because we say things in your language  
like:  
It is so blue.

Just because I have a limited vocabulary in the world of words  
does not in any way mean my world inside of me  
is so limited.

This respondent also highlights the potential risks in deciding to articulate honestly the nature of her world experience and understanding to an NT world where the frameworks for interpreting 'difference' may be damaging to her:

R6: I also used to work at a copy shop with copy machines.  
Was I able to produce more copies than anybody else  
because I understood the physics behind the machines?  
I also called the machines by names and talked to them.  
How naive, how crazy.  
I loved to put my hands on the machines and feel them purr.  
Is it just that I was sensitive to the physical needs of the machines  
or was there more?

I guess I shouldn't tell you this.  
I can be labeled naive, even schizophrenic.

This respondent also draws attention to the dilemmas and choices facing her as she negotiates a world of NT norms and expectations. She describes the personal cost to herself of finding strategies to manage and deal with her experiences in a way that is considered more socially appropriate. Ultimately she sets out the personal choice to follow her own path in an NT world.

R6: Again in these pages you talk about outgrowing some of the behaviors  
by learning and practicing to compensate.  
I have learned that my autism is like tourettes.  
I have heard people with tourettes say that if they spend their energy trying to not be tourette like  
the behaviour will come out later in another form.

Yes, I have learned how to pass in this world.  
How to look and act like an NT.  
But it comes at a cost too big to my soul.  
To kill me to act more NT  
comes out later  
by my beating my head on the wall,  
by my feeling intensely lonely in a crowd.

My autistic skin has not subsided just because  
I was spanked into compliance for so many year  
or even bribed into being less weird.

By my denying the way my brain works  
I am denying me.

... about fitting in

at the age of 39 i no longer want to fit in  
i wish only to accumulate enough NT money  
to be able to be myself  
without being a street person

These issues, if shared by others with autism, may be seen as limitations for the researcher in accessing full disclosure and understanding of sensory-perceptual experiences through approaches which utilise self-report.

In terms of overall analysis, one respondent, R9 while generally supportive, suggests that my analysis is insufficient to account for sensory-perceptual experience in autism. She posits, in addition, a problem with habituation and an orientation to detail rather than the whole.

R9: I find your theory of attention interesting but not sufficient for explaining the problems with sensory processing. I would like to enter also a problem with habituation (delayed) (what you at the end mention as getting used to) and a perception which is orientated towards detail rather than wholeness into that theory.

At the level of neurobiological theory she suggests that Margaret Bauman's concept of immature neuronal circuits may be helpful in understanding sensory difficulties:

I heard Margaret Bauman, neurologist speak on the neurobiology of autism at a conference a couple of weeks ago, and she mentioned some interesting new theories. One is that the autistic brain has some circuits which are meant to deal with life in the womb, but because of some problem in development these are not replaced by more mature circuits. I found this interesting in a perception perspective (she did not, however, make that connection). My thoughts are that in the womb you do, obviously, not need a system which is really skilled in handling sensory input, so maybe this then affects sensory experience if you have these prenatal circuits instead of the mature ones.

The comment of Respondent R6 is generally affirming of the usefulness of my analysis. However, implicit in aspects of her comment, is the suggestion that she views her difficulties in relating to people as an expression of a general lowered threshold for dealing with sensory stimuli. She suggests that her difficulties relating to people, has, because of her 'extra sensitivity' (to all aspects of the world including emotional stimuli) to do with the level or intensity of sensory noise which they emit. She suggests that it is this aspect of people that she finds difficult and which leads to her withdrawing from them. She indicates that she can and does form attachments to people who are quiet and non-intrusive.

R6: But again I think it is more that I am extra sensitive.

I ignore so many people

because I am picking up so much from them.

I have to shut down as much as possible to survive.

It looks like am rude and snobby and ignoring them.

But in reality I am feeling them too much

and I leave their presence to preserve my sanity.

R6: This does not mean I cannot attach to other humans. It means I attach to

certain humans who do not overload my senses. I can only be around other

humans a certain amount of time a day. Therefore I appear aloof and detached

to most people because I have to save myself for the people I love and the

people who are interested in my interests.

Thus from this perspective, difficulty with social interaction skills such as eye contact is due to enhanced sensitivity towards the social and emotional content and meaning of such exchanges and not as is implicit in my account,

due to an underlying impairment in shared emotional connectedness and understanding with others.

R6: difficulty with eye contact

again it isn't that i feel too little

it is that i feel too much

for me the eyes really are the gateway to the soul

i see way too much

this is also true with understanding NTs

and their emotions

NTs lie a lot

their faces and actions say one thing

and they say they are "fine"

I do not do that and I do not understand why I would want to lie.

Of course this categorizes me in literal thinking territory

but it is more that i find nt culture a bore sometimes

too predictable

and not very close to their true emotions

for me the confusion

is

why is the nt world so full of games

One respondent also raised the issue of specificity of these experiences to people with autism. While viewing these experiences as more highly typical of people with autism he nevertheless quite correctly points out that people without a diagnosis of autism may also experience unusual sensory-perceptual experiences:

R1: I agree with most of your analysis. I have an extremely analytical mind. Hence, I can see much of what you comment on, as being very specific to autism, and to some extent to all people at large. That is, I feel that much of what you say in your analysis, is also true of all people, although perhaps to a much lesser extent than is typically found in autism. For example, many people have unusual sensory- perceptual experiences who are not autistic. But I nevertheless agree that such sensory-perceptual imbalances are much more highly typical of autistic individuals than they are of all people in general.

## ***2. Impaired Attentional Beam***

The concept of an impaired attentional beam received very positive affirmation in respondents feedback. All respondents identified difficulty in flexible and automatic attending to events around them in keeping with core elements of the analytic account.

Respondents highlight difficulties congruent with the idea of an attentional beam which may be 'too-wide' or 'too-narrow':

R6; And so I find your analogy of a spot light beam that seems to either be too wide or too narrow and doesn't automatically slowly widen or narrow like the rest of the world, rather fascinating.

A neurologist recently said I can't close the windows to the world out there.

That sounds similar to your saying I can't naturally / automatically make the

beam narrower except to make it too narrow.

R1: The autistic mind (and mine in particular) seems to be mainly disconnected to anything, everything, and whatever. My "attentional beam" is anywhere and everywhere, all at the same time.



... Crowds, whether inside a building or outdoors, blow my mind with an overwhelming intensity of sight and sound. I hear and see everything all at the same time. It is all one conglomerated mess of anything and everything, all mixed together.

R3: Quite often what happens is that if I am focused on something and a person approaches, I have a huge "startle reflex" reaction. One person where I work (with whom I have a good relationship) tells me that he does everything he can think of to avoid startling me. He walks noisily and coughs outside the door, etc. But if I am concentrating on something, nothing he does will prevent me from going through the big startle reaction. One day I was at home, getting ready to leave for work, when I looked out the window and saw someone in the yard. I knew who it was and therefore prepared myself to speak to him (to say "hello") as I passed by. And yet, my "attentional beam" was so focused on what was going on in my mind that when I actually did leave the house, less than a minute later, I had a big startle reflex when that same person came into my field of vision again. (The startle reflex sends a flood of adrenaline through my body and is not pleasant. It also seems to upset other people when I react to them that way.)

R2: -- Yes. I often do kind of "trance out." I did this a LOT as a kid.

A number of respondents identified in particular, delay or difficulty in switching attention flexibly from one attentional focus to another:

R7: I agree with your perception that autistic people have a disorder of the "attention beam". I still have more need than most people to be able to focus attention on one thing at a time, and find it more difficult than most people to switch from one item of business to another.

R2: I forgot to mention that I cannot do "multitasking," as people have called doing two things at once, like phones and word processing.

R3: I'm sure you're right about the "impaired attentional beam."  
Although I've never been tested for it, I have been assuming I have CAPD (central auditory processing disorder). But maybe not. Maybe it's simply my impaired attentional beam. If I am focused on something (e.g., at work) and someone (e.g., my boss) comes up and talks at me, I have to stop myself, stop him, and then ask him to start over - because I will have no idea what he has been saying to me. I need to have an interval of time during which I detach from one focus and switch to another.

When spoken to unexpectedly, R3 describes a delay in processing sound for meaning that she suggests may be explained by the idea of an impaired attentional beam:

R3: Getting back to the CAPD that may be attentional beam instead.... I also find that quite often if people speak to me unexpectedly all I hear is sound, not words. The most recent example I can think of happened last week. I was walking to work, my mind absorbed in thought, and a person in front of me made mouth-noise at me. I walked around him and went on my way. About two blocks later, some part of my brain clicked in with the realization that the person had said to me, "Nice shirt." And, in fact, I was wearing a nice shirt that day. Then I felt a little bit bad that I had not been able to accept his words as they were spoken so that I could have responded in some friendly way. But it was too late, of course.

Support is also provided for the notion of difficulty in maintaining efficient selective attending to events, especially in sensorially busy environments. This is described by a number of respondents as effortful and problematic:

R1: Impaired "attentional beam". Stress and strain is the name of the game. Indeed, if people could visualize, even for a small moment, the super intense effort required for me to maintain sufficient control of my surroundings so as to avoid the insane asylum, they would probably go into shock and perhaps

never recover. In a very real sense, living for over fifty years with autism, is paramount to a thousand years or more of "normal" life.

R2: -- \*\*\*Always\*\*\* -- cannot concentrate when there is other noise in the background; get distracted.

R5: I find it hard to concentrate when I'm in busy, high visual and auditory stimulus environments such as my workplace, stores and other crowded areas. Trying to attend to everything that's happening also makes me experience "inner noise," which are thoughts jumping around in my head.

At these times I'm disorganized and jump from task to task

One respondent offers an alternative conceptualisation, that of 'monotropism' to describes her tendency to function with what the researcher conceptualised as an over-narrowed attentional beam. Under this conceptualisation sensory overload or shutdown is the result of pressure from information being presented through multiple channels simultaneously to an attentional system that can only deal with one aspect at a time:

R8: When you talk (write) about 'disordered attention' I experience this not as 'disordered' but 'ordered' attention. It is selective, not so much by choice as by my being monotropic and only able to focus in on one thing at one time.

It's the same with my senses and emotions. I 'home in' (as it were), (so to speak), on only one element at a time. If more than one is presented to me then I only 'see', hear, taste, smell, feel etc. one and the other either moves into the background, gets missed or, if it is very intrusive, it may prevent me from giving my attention to anything!

When lots of 'channels' (visual, auditory, tactile etc) are challenged simultaneously, or when I am tired and not so able to cope, then I can experience 'over load' and may either switch down or explode!!

R7's 'need' to focus on one thing at a time may also reflect a similar bias towards operating with an over-narrowed attentional beam. Under this researcher's analytic conceptualisation this evidence would suggest that some individuals may have a bias or tendency towards operating at one or other end of the attentional continuum, in this case an overly-narrow attentional lens while others may be more prone to operating with an overly wide attentional beam.

Respondent feedback also supported the idea that a range of factors such as interest, motivation, mood state, energy level and activity affect the efficient working of the attentional beam.

#### *Interest and motivation*

R1: Speaking of attention, I rarely pay much attention to anything around me, unless it affects me directly. I am a perennial daydreamer. Keeping my mind centered on just about anything for more than a few seconds requires supreme concentration and effort. You might say that my mind (such as it is) is more or less continually gazing off into the obscure oblivion of nowhere in particular, or as I sometimes refer to it, outer space.

In pursuit of special interests and/or coupled with other exceptional abilities e.g. perfect pitch, the ability to selective attend may be enhanced:

R1: My hearing is generally extremely acute. I can hear conversations, even whispers, at a long distance away. I also have perfect pitch. When I listen to an orchestra or symphony, I can pick out individual instruments and tell exactly what notes they are playing.

R1: I can block all but the most severe pain with great efficiency. I often wonder why so many other people are always complaining about aches and pains. I have walked for miles on sore aching feet and I just keep right on going. I walked half the distance on a 1500-mile bicycle excursion several years ago.

*Anxiety and mood state*

R1: Inefficiency and distraction. Oh yeah. Definitely. I consider myself extremely fortunate if I am ever without them. And yes, when I am relaxed (which means I probably know a lot about some particular situation), my emotional state and attention beam are much more efficient.

*Age*

Respondents feedback indicated that the idea that the working of the attentional beam becomes more automatic and reliable with age is true only for some individuals, although in part this may be related to factors such as interest and motivation which have already been identified;

R3:... and, as you describe in the 5th paragraph under "Impaired attentional beam," age makes a big difference. When I first went to college (when I was 17 years old), about 95% of it failed to hold my attention and I dropped out. Not until I was in my 40s did I find myself keenly interested in the process of education/learning to the extent that supported me through finishing my BA degree.

R6: I am not a person whose senses have calmed with adulthood. I have no idea what the people who told you they are doing better with these things were talking about. For me my I.Q. has figured out more coping strategies. But nothing stops the wide beam as you would call it. I am always at risk for sensory overload.

*Engagement in low level activity*

R3: In the last paragraph of that section, you refer to strategies used to help focus the attentional beam. Many online autistics report using some variation of "doodling" to help us pay attention to speakers (e.g., in a lecture class). Without the doodling, we will be unable to "hear" (focus on and "take in") what is said. My form of doodling is verbal. I don't draw little pictures, I write lists of words that fulfill some criterion chosen for the moment.

R5: I also notice that I concentrate much better when eating and was never able to study unless I was eating at the same time.

One respondent suggests that the lack of automaticity in the working of the attentional beam should be seen as part of a wider difficulty with automatisisation which affects all aspects of her functioning:

R9: The problems with perceptual automatisisation are very accurately described, and I personally believe you could use the automatisisation thought on other parts of the disorder (social difficulties, for instance). I have for example also poor motor automatisisation which means I have to concentrate on movements too. The problem is that we don't know exactly what 'automatisisation' is and where in the brain it is located.

One respondent appears to offer support for the notion of narrowing of the attentional beam as an adaptive or coping strategy that is described as 'tuning out the world that hurts me'. However, this respondent suggests that the notion of an over-focused beam does not fully reflect the nature of her internal 'own' world:

R6: I think that it isn't quite like you think

about the more focused beam.

I think that what you call the more focused beam is when I am tuning out the world that hurts me and I am in tune to my own world. Instead of the world penetrating and disturbing my internal world, I am in tune to my world and then I can sometimes match it to some of the external world.

Another respondent indicates that overload can lead to 'switch down' which she does not describe in any further detail but which is reminiscent of the shutdown described in the published accounts. Two respondents indicate that sensory overload can lead directly to challenging behaviour.

R6; When I get overloaded  
my body goes crazy.  
I beat my head on the wall and keep saying the same phrase that is stuck in my head over and over.  
I bite my skin and scratch off my skin.

R8: When lots of 'channels' (visual, auditory, tactile etc) are challenged simultaneously, or when I am tired and not so able to cope, then I can experience 'over load' and may either switch down or explode!!

However, R6 suggests that it may also lead to vivid night dreams

R6: Sensory overload comes out inside my skin.  
Yes, all these external stimuli  
outside of me  
are bombarding me  
but without the comfort of physical touch  
all that stimuli must come out somewhere.  
It comes out in very very vivid night time dreams.



That are very very real to me.

### **3. Sensory-based World**

The concept of a sensory-based world resonated strongly within respondents feedback with all participants offering comment supportive of this idea.

There was support for an attentional orientation to and comfort in the physical and sensory world and corresponding difficulty with people and the social world. A number of elements are represented in respondent comments: the sensory-physical world is described as less problematic than the social world where interaction may be experienced as problematic or unpleasant; there is a lack of emotional connectedness to people and a heightened emotional salience of the physical and sensory world; and an absence of the usual distinction between the animate and inanimate world

R1: Attentional orientation to a sensory world. This describes me to a T, as well as from A to Z, exactly as you have described it. ... A problem in understanding people and emotion. And the physical world is less problematic than the social world. You got it, Meena. That's it, definitely. And I am constantly gazing at anything and everything but people.

R7: It is also a valid point that autistic people focus on things rather than on people, because the latter are fundamentally more difficult to handle.

R1: Emotions. I usually don't having any real feelings for people. I am kind, gentle, and caring. But I have little, if any, emotional sensitivity or perception. Nor do I have any close feelings for animals. They are all like moving objects. That's about it. Essentially I am a highly refined robot. Age and experience have made me a good actor, but I am still a programmed robot.

R3: I am another autistic who prefers to interact with objects (as in the sixth paragraph in the "sensory world" section). I've always preferred interacting with animals (non-human animals), and, for reasons of convenience (and expense), most of my interactions are with the non-breathing kind of animal.

R6: But again I think it is more that I am extra sensitive.

I ignore so many people

because I am picking up so much from them.

I have to shut down as much as possible to survive.

It looks like am rude and snobby and ignoring them.

But in reality I am feeling them too much

and I leave their presence to preserve my sanity.

Respondent R3 felt that this concept of an orientation to the physical and sensory as opposed to the social world helped her to understand why her childhood memories differed from those of other people in containing no people:

R3: I was glad to read in the section on "A sensory world" an explanation for the fact that none of my childhood memories contain any people whatsoever. This has always puzzled me, since I found out that other people's memories are full of people. Almost all my memories are of places, and they feel very spatial. Oriented in space.

Respondent feedback also affirmed particular difficulty with social or affectionate physical contact:

R2: -- [I] Feel very uncomfortable when touched by other people at all. Uncomfortable shaking hands with someone. Being sexually intimate with someone is out of the question

R5: I also dislike close physical contact like hugs and kisses, especially

when saliva gets on my face. According to the record written when I was diagnosed at age 3, unlike other infants, I showed no desire to cuddle during my first year of life.

R3: Your comment (at the end of this section) about shaking hands becoming "less problematic with age" is true for me. In my case, it helped greatly that I came to have a reason for it. I work in a university's school of international studies, and we almost always have visitors here from different countries around the world. Some of them, I know, are trying very hard to behave as they think they need to in order to fit in and appear polite by U.S. cultural standards. This often includes their perception that they need to shake hands with everyone. I see it as part of my job to help them out, so if anyone puts out a hand to me, I shake it. Sometimes the hard part is that I am supposed to be able to go on listening (and understanding what they say) while going through the business of hand-shaking.

Feedback affirmed the emotional salience of the sensory and physical world. Respondents identified a number of aspects to this experience:

*a source of pleasure*

R2: Pleasure and comfort in specific tactile fascinations or experiences such as the feel of particular fabrics or the experience of being encased in blankets or water.

-- Yes, the feeling of sunlight and of water -- I like taking hot baths a lot. For sheets and blankets I prefer flannel next to my skin.

R5: One tactile experience I crave is the kind of tickling one experiences when a housefly lands on his/her arms, legs or back and crawls over them. As much as certain edges like those on a piece of paper bother me,

I love the feel of freshly cut hair and had combs taken away from me in

grade school when I combed and played with my hair in class the day after getting a haircut.

*a source of comfort or protection*

R6: When I fixate on every helicopter that goes over my head, it is because it sounds like my heart beating. It matches my own body rhythms and feels like what I expect mama's arms would feel like others.

When I was 2 and 3 and 4 I would climb into the back of our VW bug (tiny car) and squeeze into the section right over the motor and fall asleep to the hum of the motor. It was my chance to be rocked to sleep without being hurt by another's touch.

I lay on big rocks in the woods because their smooth cool surface is more comforting than any human touch.

*a source of companionship/friendship*

R3: At the moment (since my mother died in 1995), I live with about 280 bears, plus a few other assorted non-bear animals, and I've spent the last three years learning how to make them myself. I also have some "friends" who would be even less comprehensible for non-autistic people, I suspect. For example, there is a spot of something on a sidewalk that I relate to every day as I walk to and from work. I think it might be putty, but it stays there and has a very nice shape (like a comma that is about one-half inch in diameter).

One respondent R6 clearly suggests that her inability to find comfort in people resulted in the seeking of comfort in other ways, including comfort and pleasure in the physical world:

R6: Most babies and humans naturally find comfort from that outside world. They get cuddled, sung to, fed, etc. But as my mother said, "If we tried to pick you up, you would scream!" One of my older cousins said, "If we let you sit or stand in the corner of the room away from the activity then you would look up every once in a while to see what the rest of us were doing."

R6; So where does an autistic find comfort, or at least this one? From inside myself and from unintrusive introverts and repetition.

I couldn't get love from the usual places/persons so I found comfort in other repetitive ways.

Most children touch in with their grown up humans repetitively. You see NTs are just as repetitive as autistics, just that they don't notice themselves because they consider it normal to give do culturally repetitive things.

Hugs,

kisses, hand shakes, pats on the back, hellos, how's it going, merry christmas, etc.

But all those things hurt me.

So I had/have to comfort myself and a few very creative people have found their way into my world.

Respondent R6 also affirms the absence of any recognition of people as 'special' and her preference for inanimate objects because they 'quieter' than people. Indeed 'NT' treatment of objects is perceived as 'callous'

And machines give off a quieter signals.

There is no line between animate and inanimate for me.  
It is just more like a spectrum  
as to how loud each person/ thing is giving off signals to me.

Machines and animals and trees and rocks  
are just quieter in their souls than loud complex people  
So when the doctor tells Donna Williams to not  
apologize to the rug for walking on it.  
I think the doctor just can't hear the rug  
like Williams can.

To tell her to ignore the rug  
is pretty callous in my opinion.

I would rather be a being who  
is sensitive to the needs of all that surrounds me  
than callous like so much of humanity.

Other aspects of the concept to receive support included the notion of a non-reflective grounding of awareness in the present and a literal and concrete way of interpreting experiences:

R1: I live (perhaps, maybe. It's hard to tell really.) in the present, for the most part. With great difficulty I can sometimes reflect on the past and the future, but it generally doesn't come naturally.

R1: Over-literal way of interpreting and responding to the world. Although tempered by time and experience, this still affects me quite intensely.

Respondent R5 describes a lack of perspective towards past unpleasant events which results in them remaining vivid and real:

R5: I also have the unusual ability to remember all unpleasant body experiences, including ones experienced at age 5, forever. To this day I remember in vivid detail the vomiting I had with

the stomach flu at age 5, the heavy bleeding I had at age 18 and the unpleasant gynecologist exam I had that year. No matter what I can't forget these past events.

Respondent R6 while pointing up the difference in her experience of time and her interpretations of events takes issue with my use of the descriptive phrase 'naive sense of wonder' to describe her experiences. She sees this as judgemental and value laden and argues strongly for the validity and value of her framework of experience:

R6: There are some places I disagree  
or see the same thing differently.

You use the phrase  
"a naive sense of wonder".

I think this shows you are thinking linearly.  
As if life is dot that progress up a line.  
That the object is to move away from childhood.

A lot of autistics besides myself  
say there is a very thin line between our childhood and now.  
We don't see time as a line.  
Instead we feel things in the past, in the present, and can see a lot of  
our  
future at the same time.

We have not let go of our sense of wonder.  
But that does not make me naive.  
Personally I think keeping my sense of wonder  
makes me more intelligent than most NTs.  
It makes me open to more than one answer to questions.  
I open to more possibilities.



In my opinion,  
it is the NTs who are naive to think  
there is only one way to see.  
Although  
it is overwhelming to see more than others  
I think  
I prefer my way of seeing things.  
I would never want to think  
adulthood means moving further down the line away from childhood.  
I love including instead of excluding the wonder  
I feel  
when I see a piece of art for the first time.  
I love the way I feel, so alive, when I walk barefoot in the mud.  
I love that I play soccer goalie  
so that I can fly through the air.  
I love the way I feel when the trees are waving at me  
telling me they are pulling for me.  
Telling me to defend those of us  
who have said little in this life.  
I love the way I can stare at one picture for hours on end.

Similarly R6 takes issue with the notion of a non-reflective aspect to her experience. She identifies 'difference' as a result of thinking in pictures that is difficult to articulate in words:

R6: I finished your paper.  
The only thing I that stands out  
is the assumption that there is  
non-reflective sensory experience vs reflective social experience  
that I supposedly evolve into  
to fit into the NT world.

Again just because  
I don't always have words from you language  
to describe  
my wonderful sensory experiences  
doesn't mean  
it is non-reflective.  
It may be non-reflective as far as the english language is involved  
but believe me  
I have hundreds of pictures going through my system,  
connecting to the picture in front of me.  
Yes, I am collecting all the data from the picture in front of me.  
Experiencing it totally in the moment.  
But I can't stop all the other pictures being there too.  
As a nonverbal child until the age of three  
and then barely verbal until the age of 8,  
I was not an amoeba reacting only to inanimate stimuli,  
cut off from the human world.

The world of humans that were saying blah, blah, blah,  
was included in what I was sensing around me.  
I was processing and reflecting in my own way  
I just couldn't give  
back the formulas I was developing  
in an NT way.

In addition R6 also provides description of her early memories of her father that suggests an attachment and pleasure in his voice which is somehow separate from the wider social-emotional context of relationship:

R6; But my father talked to me like I was an intelligent being  
and explained everything that happened in his exciting work  
as one of the nation's first computer programmers.  
So my father would come home from NYC

and my mother would be totally occupied with my brother.  
And my father would find me in my crib where  
I insisted on being  
and he would tell me all the adventures of his life in NYC.

So my father's voice became my comfort and link outside myself.  
I was loved by his voice and his treating me like an intelligent being.

The interaction between the absence of social connectedness/shared social framework for viewing the world and attentional difficulties is highlighted by one respondent. As a result social interaction of all kinds is extremely difficult:

R3: But even "every day" kinds of one-on-one interaction - e.g., with a co-worker or with a store clerk - are socially wearing on/for me. In social situations we must strive not only to focus that attentional beam but also, simultaneously, to sort through all the potential objects of focus and identify the ones deemed appropriate by "normal" people. And we must hold that focus while excluding from our "beam" all the other potential objects of interest. It ain't easy.

R3: This may be a contributing factor in the much-discussed (online, among autistics) extreme difficulty we have in making ourselves feel interested in many of the things in which other people expect us to interest ourselves. There are some subjects and some ideas (even some terms) on which I have an incredibly hard time making myself focus, simply because I am unable to want to. It's as if the parts of my brain that are supposed to handle those subjects/ideas/terms are supposed to have a sticky surface (like Velcro) but instead are smooth and slippery. The ideas slide right off every time, along with my attention.

#### **4. Perseverative Bias**

Respondents feedback also provided support for the concept of a deeply ingrained bias to repetition and sameness. There was support for the idea that events already within awareness tend to repeat or stick, that there is an attentional orientation to repetitive and predictable events and a general preference for sameness that pervades many aspects of life. This bias results in difficulty in switching attention from one focus to another.

R3: The aspect you call "bias" (#2 in your list under "Analysis") has been discussed by HFA/AS people online as a matter of inertia. It takes work to switch focus because we have to overcome our inertia. Maybe autistic people have more inertia than non-autistic people.

R1: Within my awareness (which is somewhat synonymous with my memory), various events may "stick" and the inbuilt "pre-wiring" may prevail, leading to future repetitive events. And yes, I do tend to switch my attention from one thing to another very slowly and often reluctantly.

R2: -- I do like repetitive blinking lights, "psychedelic" light shows, screensavers, stuff like that to watch over and over. Get a bit entranced by this kind of thing and have done so as far back as I can remember.

R2: A preference for the familiar, and a difficulty in accepting change within familiar visual environments.

-- Yes, this is why I prefer fulltime jobs that I can hold for many years, like when I had one job for 22 years. Being a temp is VERY hard for me because it takes me longer to get used to new environments than it does others. And this is no doubt why I got laid off from that 22-year job in the first place, partially at least -- because they wanted us to start to learn other tasks at work and I wished to stay with the repetitive dictaphone/ word processing job that I'd had for all those years; I had no interest in learning anything new at work. I was very resistant to anything new.

Respondents identify a number of factors which may contribute to this bias to and comfort in repetition and sameness:

R3: One reason to prefer repetition and sameness is that it is work to "shift gears." Work, work, work, all the day long.

R3: In the section on "A bias to repetition and sameness," I suspect one element you don't explicitly mention (as I read your words) is related to a need to feel in control. It's true that repetition is soothing. It's also more predictable. If I can predict what is going to happen, I don't need to worry about the extent to which I may be overwhelmed by the unexpected. And if I can predict what is likely to be expected of me, I can prepare myself for it better. For example: I am fortunate to have a part-time job (four hours per day, five days a week) where I am alone much of the time. A new person was hired recently who feels the need to "check in" with me regularly; she is much more social than I am (naturally!), and I find her draining (although she's very nice and I am able to appreciate her good qualities). Her job is part time, too, but she works two full days and one half day a week. I definitely want to know in advance when our hours are going to overlap, because I prefer to have some "advance warning" about social interactions. It's harder on me to have her appear unexpectedly, expecting a conversation with me than it is if I know she is around and may stop by. (Or course, I also feel that "knowing she is around and may stop by" as a kind of tension and energy drain. But it's not as bad as the shock and the instant, clutch-slipping reversal required when she appears and I thought she wasn't working that day.)

R6: I've been thinking about the repetitious sounds...

When some people are trying to center themselves some of them seek quiet.

I wonder if I am trying to replace  
being held by my parents,  
if I am trying to replace the basic sound of the heartbeats I never got to  
hear.

What comforts me?

All helicopters, especially Vietnam helicopters.  
I was born at the end of 1961  
and most of my childhood my parents  
were watching the news with the Vietnam conflict  
and I would touch the TV whenever any helicopters  
would come on the TV.

When the TV show MASH used to come on  
I wanted to only see the beginning sequence  
just to see the helicopters....

I love certain beats on drums, especially Native American  
drumming that is actually trying to replicate  
the human heartbeat.

I love it when it feels like the drums  
are piercing my through my heart.

I love to fall asleep to the hum of a car engine.

I have to fall asleep with a fan soothing my skin,  
but I also love listening to the sound.

I love the sound of water in streams and rivers.  
So when I am in nature I am not seeking the quiet,  
I am seeking the rhythms that soothe me.

Certain music rocks me and totally gets me lost in me.

Two respondents suggest that unpleasant or stressing events may exacerbate the tendency for thoughts to 'get caught in a loop'

R5: I find that an unpleasant stimulus, be it a sad song or unpleasant doctor appointment, is impossible to forget. The sad songs stick in my head and haunt me.

R6: But also there is something going on inside my brain in which pictures and sounds get caught in a loop so to speak.

I have met other autistics who like myself are more interested in the sounds of words than their meaning.

We are big Dr. Suess fans.

We can't stop the sounds from going round and round in our head.

These things happen more often when I am overloaded from all the sounds that do not match me.

In particular when too many people have talked to me.

Then their sounds get trapped inside my brain and it takes a long long time to let go of them.

Even the sound of my own voice can haunt me for hours.

Respondent R1 also includes repetitive and stereotyped behaviour and movement as another strong characteristic of this tendency. He suggests that once started on an activity it may be difficult to stop



R1: Repetitive play and stereotypies. I may never outgrow them, as long as I am autistic, which I probably will continue to be until I reach the happy hunting grounds.

R1: That's another thing. Once I get occupied with certain types of endeavors, I can't seem to quit. Like the Energizer battery, I just keep on going and going and going.

Respondent R7 however, regards this tendency towards repetition and sameness as overstated within my analysis. Instead he suggests that any reluctance to engage with change is limited to what is perceived as 'adverse' change. He cites as evidence the fast pace of change in Information Technology, a field which attracts many people with autism:

R7: However, I think the idea that autistic people are averse to change is overstated. It would be more accurate to say that autistic people are adverse to change which seems to be for the worse. I think you'll find that a lot of Asperger's people do well in information technology, and not many fields change faster than that, but most of the change there is for the better.

## **5. Hyper-sensitivity**

Respondents feedback provided support for the notion of hypersensitivity but taken as a whole their feedback suggests that this concept alone is inadequate to account for the full range of, and variation in, respondents experiences.

General hyperacuity or an 'amplified volume' experience of sensation is indicated in respondents feedback. In addition there is support for problematic sensitivity to particular stimuli. A high degree of variability

between individuals in relation to this aspect of their sensory experience is also confirmed. Only one respondent R7 indicates that hypersensitivity is not a feature of his sensory-perceptual experience.

An amplified volume experience may occur in a number of modalities or may be confined to one modality:

R1: My hearing is generally extremely acute. I can hear conversations, even whispers, at a long distance away. I also have perfect pitch. When I listen to an orchestra or symphony, I can pick out individual instruments and tell exactly what notes they are playing. Microphone peaks or squeaks and emergency vehicle sirens about drive me crazy. I have to cover my ears with my hands to avoid the intense pain and mind-boggling volume.

...My vision, adjusted for myopia and difficulty in focusing by trifocal glasses, is highly perceptive. I can discern minute objects a long distance away.

... Flashbulbs and other bright lights are overwhelming. Cars with their lights on in the daytime, which would normally promote safety among most people, are a painful distraction to me, and could result in an accident if I were to drive a car.

... Generally, I can't stand to be touched by other people. Nevertheless, my sense of touch is rather acute. I can sense very fine and delicate feeling sensations when playing the piano, which is further augmented by my intricate sense of hearing.

R3: I'm not sure where this fits in (it came into my mind when I read, towards the end, about "establishing routines around eating and drinking"), but I think one thing many of us experience - acutely in childhood, less so later on - is a real problem with textures. Some textures are almost unendurable. And this is true in the case of food as well as things like fabric/clothing. When I was a child, there were food textures I could not tolerate. If they were forced on me, I would vomit. And this definitely was not volitional. I have a life-long hatred of vomiting. My mother (bless her) quickly learned to accommodate this problem by serving me only the food I could swallow and keep down.

The last time I encountered a food texture that defeated me, I was in my 20s

R5: I also wish to add vestibular hyper/hyporeactivity to the list of sensory abnormalities experienced by autistics. Some are underreactive and stimulate themselves by spinning and seeking swinging and similar activities. I am the opposite; as I said yesterday, I get motion sick. I never liked amusement park rides and can't even use playground swings or merry-go-rounds without getting nauseous. I always felt insecure off the ground and couldn't play on seesaws. At the pool I refused to try jumping off the high diving board. I was also slow at learning how to ride a bike and ice skate (the latter started only 12 years ago).

One respondent suggests that the experience may include an amplified experience of some internal as well as external sounds:

R2: -- Also, I cannot hear **\*\*anything else when I am chewing.\*\*** At the table, I need to stop chewing entirely when people are speaking to me because the noise being made in my head from my chewing is deafening!

Problematic sensitivity to specific events is also supported. This may occur even within the context of a general sensory impairment within the same modality

R5: From as far back as I can remember, I couldn't stand the feel of paper, kitchen counters, purses, bags, things that are soft but have edges, plastic cheese containers, edges of wooden furniture. Some paper bothers me more than others with the worst offender being the thick

paper used in copiers and laser printers (have to touch this all day at work). The edges and corners are particularly irritating to me.

R2: Problematic hypersensitivity such as distress in response to loud, high pitched sound or unexpected sound or specific types of sound such as certain voices, electrical equipment or vehicle noises. [despite being hearing impaired]

-- Yes -- cannot stand squeaky sounds, \*\*children's high-pitched voices\*\*, \*\*cartoon-type voices.\*\* And TV commercials drive me nuts!

Tactile hypersensitivity is reported as common to all respondents and includes problems with social touch:

R2:-- Hate wearing shoes, socks' seams felt too prominently, socks falling down a little in shoes bug me a lot, cannot wear sweater materials next to skin; cannot stand neckties or anything else around my neck. I have itchy, sensitive skin. Very resistant to any kind of work "dress codes."

-- Regular milk has always been too "watery" for me. Prefer evaporated, nondiluted.

R9: - pain from cutting hair and fingernails, described in my book, and I have

met several parents mentioning this problem with their children with autism

- pain from shower (i.e. water in drip form) To me this problem was the

same as with light touch (and the intention of the toucher had nothing to

do with it), everything which landed on a small surface of the skin was

very unpleasant (as opposed to taking a bath with water all around you, or

deep pressure from being rolled into a carpet).

R5: Touch: my biggest problem - I experience all four items you mentioned:

- Unpleasant sensitivity to particular fabrics or materials and certain body-care activities such as having hair cut
- Dislike of specific food textures or combinations
- Unpleasant experience of affectionate touch and other forms of social touch
- Pleasure and comfort in specific tactile fascinations or experiences such as the feel of particular fabrics or the experience of being encased in blankets or water

R6; This is how I see it. There is the world outside myself that culture calls reality. That world hurts. All initial touch burns and pinches. All sounds from others persons hurt my ears. All light hurts my eyes. All smells are overwhelming. All tastes are so intense I tend to eat bland tasting foods.

R6; The sad irony of my life is that I crave the intimacy of being held and hugged by another human but I can rarely tolerate it. Consequently the people I love and like the most most know great patience. I will not touch my mother, although she tries to grab me sometimes and give me a hug. But it is engrained in my very being that hugs hurt especially from Mama.

R6: My mother has always felt very rejected by me.  
Well, she did typical female types of affection with me.  
She tried to hold me and rock me and hurt my skin.  
Her higher pitched voice hurt my ears.

Both R9 above, and R6 are clearly of the opinion that the problems with social touch are due to tactile sensitivity and not to do with the social-emotional content of interaction:

R6; a problem in understanding people and emotion in particular  
is one of your phrases when talking about hugs

if your body is screaming in pain  
it is quite difficult to figure out your own emotions or another persons

A heightened sense of bodily discomfort and pain is reported by three respondents

R5: I'm glad you included this little talked about category because I have problems with this. For one, my sense of pain is heightened. I have very poor pain tolerance, another reason I fear doctors. I once fainted after having the stitches removed a week after minor surgery to remove an inflamed wart. Same happened when I fell on ice and scraped my hand. As with pain, I'm oversensitive to other forms of bodily discomfort, which is yet another reason I can't cope with medical appointments. I experience the routine winter colds and flus that others consider nuisances as nothing less than torture. Same for my monthly period. I have trouble with heavy and irregular bleeding due to hormone imbalance (followed by gyn for this), but the discomfort of all but the scantest bleeding is also torture. I get very stiff when I have my period and am so uncomfortable I don't sleep (the discomfort of bleeding, not cramps).

R6: All the extra pain I feel,  
especially when pain medicine doesn't work for me  
doesn't feel like  
the nervous system got signals mixed up.  
I think I am feeling extra pain.  
That I am extra sensitive to the world around me.  
That I am picking up extra signals.  
I don't think my brain just thinks I am in extra pain.

I think my body is in extra pain.

R2: -- I feel I may be over-reactive to pain as compared to others; much  
itchiness of skin.

One respondent suggests that mood and specifically frustration may trigger  
or exacerbate her tactile sensitivity:

R5: Frustration aggravates my sensitivity; the feels of objects involved  
in  
frustrating tasks like housework, looking for things (I have trouble  
remembering where I put things) and food preparation (frustrating  
because of bad hand function) always start bothering me.

This respondent also highlights the role of these sensitivities for her in  
precipitating outbursts of aggressive and challenging behaviour:

R5: All my life I've been destructive because of anger and rage evoked  
by  
touching objects and textures that bother me. I've been in trouble for  
breaking kitchens in apartments and chipped teeth biting things. I can't  
handle paper without ripping it or picking at the edges and have to  
keep  
a napkin under my hand when I write.



Respondent feedback also widens our understanding of the developmental course of hypersensitivity. The tenet that it attenuates with age holds only for some individuals. For others it may continue or even exacerbate with age:

R1: Hypersensitivity. Contrary to other of your participants, my hypersensitivity has, if anything, increased with age. I remember one experience when I was in a physics class in college. The instructor performed an experiment to show how various people have different levels of sound sensitivity. He used a special machine which generated a pure tone that gradually increased in pitch (frequency of vibration). He began the experiment by having everyone in the class to raise their hands and then, one by one, lower their hands when they could no longer hear the increasingly higher pitch of sound. After a while, there was only one person in the class with their hand still raised. That, of course, was me. The other students thought I was joking. But in truth, I could still hear that tiny, whiny, and thin, but nevertheless audible, super high tone. As you have intimated, there may well be a certain amount of "organic hard wiring" going on within the brain itself, through perhaps both innate development and sensory experience.

Respondent R7 however, does not identify hypersensitivity as an aspect of his sensory-perceptual experience:

R7: I personally have not ever been hypersensitive to sounds, light, smell etc. but, obviously, a lot of other autistic people have.

### ***Hypo-sensitivity***

Respondents feedback also provided evidence for a general category of hyposensitivity or underreactivity which may be considered a 'reduced' as

opposed to an 'amplified' volume experience of sensation within a modality: Hyper-sensitivity in one modality may exist alongside hypo-sensitivity in another.

R2: -- No in fact I am \*hypo\*sensitive [vision]-- I crave \*\*more\*\* stimuli such as this than most people I know -- I prefer intensely bright colors and lights.

R1: My sense of taste is not very profound. I can eat most anything. I seem to have a cast iron stomach. I love spicy food.

Problematic sensitivity to particular events may occur even within an overall context of hypo-sensitivity within the same modality

R2-- I like HEAVIER scents than most people I know of, except the smell of urine in men's rooms is very unpleasantly overwhelming. And I am oversensitive, I feel, to others' body odors and breath.

Poor proprioceptive body awareness and hypo-sensitivity to internal body states is reported as a problem by a number of respondents

R1: Relative to internal body states, I probably wouldn't be aware of my own existence if wasn't so blatantly obvious. Temperatures have to be extreme heat or cold before I pay much attention to them. Minor variations in temperature don't bother me one bit. I can work in the hot sun or in a cold room, with no problem at all. Indeed it saves me on energy bills. I haven't had the furnace on hardly at all this winter, even when the room temperature is below 60 degrees Fahrenheit. And in summer, the temperature can be 85 degrees Fahrenheit in the room and it feels just fine.

R9: Finally, another thing is the problem with muscle tonus, which as I understand it is regulated by sensory cells inside joints and muscles. Many people with AS/HFA that I've met have a problem with estimating how much

force or muscle tension is needed to shut a door, or put down a glass etc.

This may lead to using too much or too little muscle power.

R6; I feel like I don't fit in my body.

It is like I checked out the wrong species  
or that I got somebody else's hand me downs.

My body

is something that I drag around behind the real me.

That is not me in the mirror.

There is a connection missing between me and this body.

I don't understand I am hungry.

And when I start to eat

I don't understand I am full.

I don't think I run into furniture that has been in the same place  
for years

because I am not paying attention.

I think I can't feel the space my body occupies

and so I miscalculate the space between me and the solid  
body in which I run into.

But of course something I can't feel very much

is something I don't pay very much attention.

So that means it is both/ and.

Hyposensitivity may lead to both 'positive' and 'negative' consequences. On the one hand a reduced sense of pain contributes towards enhanced feats of endurance for Respondent R1. On the other his reduced reactivity to smell can lead to social difficulties.

R1: I can block all but the most severe pain with great efficiency. I often wonder why so many other people are always complaining about aches and pains. I have walked for miles on sore aching feet and I just keep right on going. I walked half the distance on a 1500-mile bicycle excursion several years ago.

R1: My sense of smell is practically nonexistent. This has resulted in many embarrassing situations. If I forget deodorant or expel occasional flatulence, I may not be aware of it. But practically everyone else is, and it can be very disturbing, in a close social work environment, to my coworkers. On the other hand, I used to live on a farm. Smelly manure didn't bother me at all.

Indeed some individuals report that their experience can fluctuate between over-reactivity in one situation to under-reactivity in another. Respondent R6 suggests that whereas she is generally over sensitive to pain, participation in physical sporting activity level may lead to under-reactivity:

R6; I am one of those persons whose every sense is on high.

I didn't get just a few.

I got them all.

Except if I move around a lot and play sports in my own clumsy way, then my

the touch sense becomes hypo-sensitive

and I ended up hurting a part of my body without knowing it.

R2: -- Sometimes under-reactive to cold; people ask me am I not cold without a jacket on?

R5: General sensory responses involving more than one sense:

Although I normally don't get irritated by sounds and sights the way I do by touch, when I'm handling something that really bothers me tactilely, the other senses also overreact. For example, when I handle the paper that bothers me, the sound of it rustling and the sight of it moving on a table will irritate me and evoke rage. In the case of the kitchen counter, the sound and sight of objects moving on it irritate me.

Respondent feedback also illuminates the complexity and interactive influences on these concepts of hypo- and hyper-sensitivity. A number of factors are highlighted by respondents as impacting on their experiences. The

role of attentional factors receives some support in respondents feedback. With regard to pain, Respondent R1 above suggests his high tolerance of pain is due to an ability to 'screen out' pain while Respondent R5 indicates that an inability to switch attentional focus exacerbates her sensory difficulties:

R5: As an autistic with sensory problems, I find midlife even harder than most. The body changes that come with getting older are enough to throw me into a state of despair and lose my zest for living. I am more aware of them than others are and perceive them more acutely than normal. Others are able to switch focus to other things and get on with life, but I can't.

Respondent R6 indicates that difficulty in applying general world knowledge to the self or failure to abstract from the general to the self is also an aspect of failure to react to internal body states:

R6; I'm not sure how much of not knowing to feed myself, not knowing to dress myself is my not feeling my body and how much is a missing link between the part of me that does feel hunger and cold and the part that knows what to do with that. I remember I had met another HFA via the Internet and she lived in Australia. It was summer where she was and winter here. She called me at 3 a.m. my time and I was on the phone about 10 minutes when she said, "I bet your feet are freezing. I bet you don't have on any slippers."

I didn't even know she was correct until I looked down  
at my feet and there were my bare feet looking back at me.

She said,

"Go get your slippers and put them on and then come back to the  
phone."

And so I did.

The weird thing  
was that I wasn't even aware  
that I neglect my feet in the winter.

I do feel the cold,  
I just don't seem to understand that slippers will warm my feet.

Scientifically I understand that slippers warm feet.  
But it is my feet that I don't understand will be warmed by slippers.  
Again it is like this body is borrowed,  
like it belongs to someone else.

And with hunger.  
At first I don't know that I am hungry.  
Then I realize I am hungry and I don't seem to understand  
that food will help me.  
I know food helps others, but why would it help me?

This respondent also raises the possibility that for at least some people with  
autism the issue of control is critical to how sensory stimuli are perceived:

R6: i heard one speaker say  
it isn't that sounds bother me  
it is sounds that do not come from me  
that i cannot control