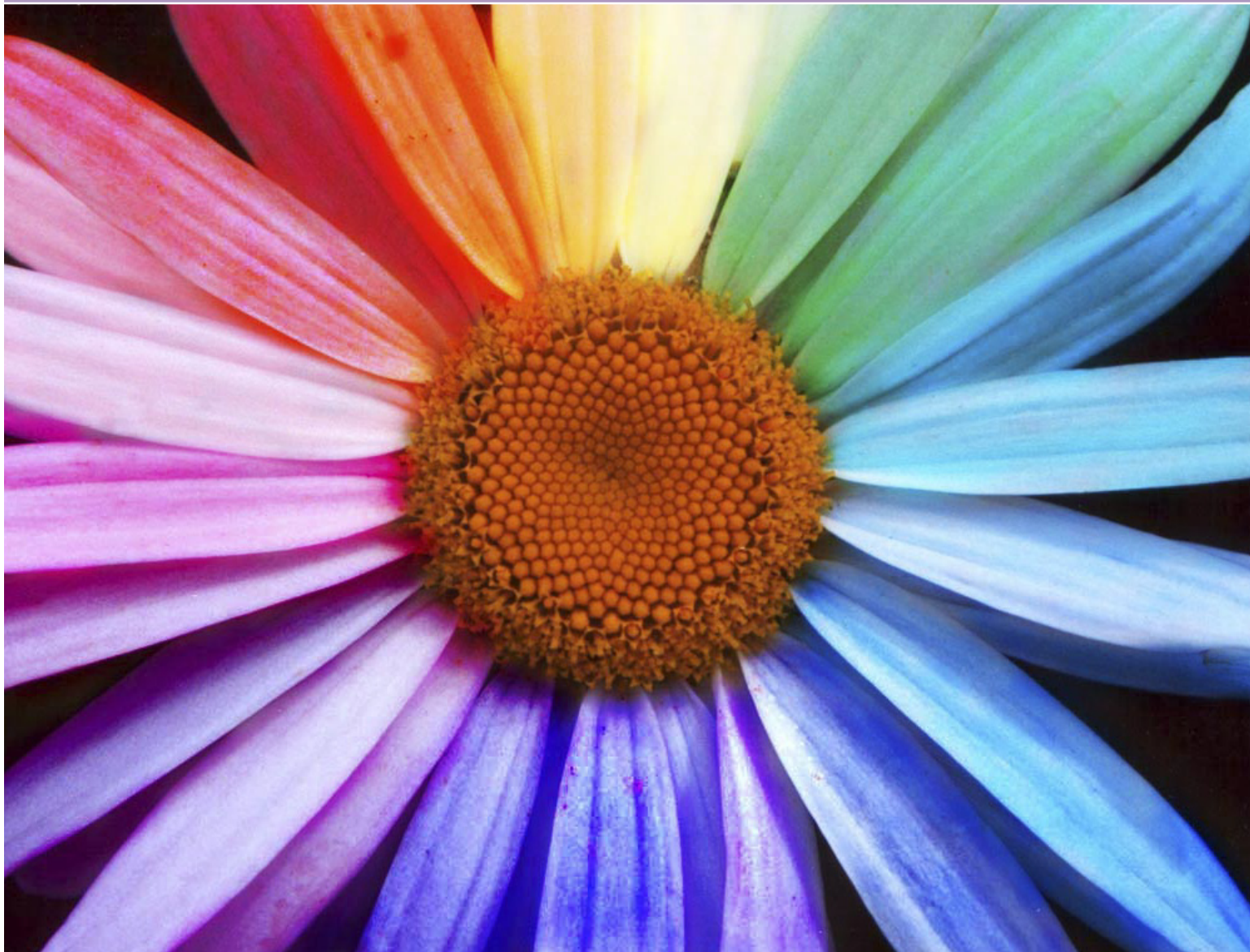


Sensory issues in Autism



'We tend to view things differently'

Wendy Lawson



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The group have been researching sensory issues in autism and working with case studies to try and understand the challenges experienced by some of the people we are supporting. The group have used the *Sensory Profile Checklist Revised* (Bogdashina 2003) to carry out profiling exercises. This has helped us identify the most common issues for people, and recognise the importance of sensory issues as one aspect of autism we should all be aware of in our work.

We are now working with colleagues in Occupational Therapy to further this work and explore 'sensory diets' for some people.

Many autistic authors have written about how they experience the world, reading their accounts has helped us learn more about this and put this booklet together. The information in this booklet is presented in the first person, based on our understanding of the real experiences of some autistic people.

Any of the books are available for loan from Firstfields Resource Library, details are on page 20.





Introduction

Learning how each autistic person's senses function is one crucial key to understanding that person. (O'Neill)

Lots of people on the autism spectrum report differences in the way their senses work. It is important for you to know a bit about this if you are supporting people with autism because it can really influence actions, responses and behaviour.

This booklet will give you some ideas and examples of how people on the autism spectrum might experience their environment. This could help your understanding when supporting people with autism.

It can be hard to work out exactly what a person's sensory issues are, because each person will experience things differently and respond in different ways. And remember that everyone's tolerance levels are affected by their wellbeing, so when we are tired, ill, run down, worried or stressed we might not be as tolerant of sensory stimuli as when we are feeling good.

We all have seven senses, described below:

Sense	Channel it comes through	What happens next
Sight	Eyes	The information travels into my brain where it gets processed for meaning.
Hearing	Ears	
Touch	Skin	
Smell	Nose	
Taste	Mouth, tongue	This is the bit which can work differently in autism.
Vestibular (balance)	Inner ear	
Proprioception (body awareness)	Muscles and joints	

We also have senses related to pain, temperature and time. People on the autism spectrum might also experience these differently.

As soon as we arrive in the world, our senses shape our experiences, helping us make sense of and understand the world we live in and everything around us (including other people). So there are two issues – autistic people have sensory differences that affect both:

- The 'here and now' of any given situation.
- The way each person has developed their understanding of the world and environment.



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If you are born with different perceptions, you have no way of knowing your individual perceptions are not the same as the other 99% of the population, until your differences are called to your attention. (Morris)

What I do realise is that I do not see the world as others do. Most people take the routines of life and day to day connections for granted. The fact that they can see, hear, smell, touch and relate to others is 'normal'. For me, these things are often painfully overwhelming, non-existent or just confusing. (Lawson)

Also, autistic people can experience fluctuations in their sensory processing, so it is very hard to be accurate about what is going on:

Sometimes when other kids spoke to me I would scarcely hear, then sometimes they sounded like bullets. (White)

Hearing gets louder sometimes... Things seem suddenly closer sometimes. Sometimes things get suddenly brighter (Oliver)

Sometimes, different sensory perceptions can cause pain, distress, anxiety, fear or confusion. This can result in 'challenging behaviour' as someone desperately tries to block out or remove themselves from unwanted stimuli:

By triggering adrenalin rushes in a state of information overload, touch and bright light and sound can become so intensely sharp that it becomes natural to avoid them. (Williams)

Some of the most common differences are:

- Sensitivity (over or under sensitive)
- Sensory overload
- Gestalt perception.
- Fragmented perception
- Delayed perception
- Distorted perception
- Sensory shutdowns
- Compensation

This booklet aims to introduce the concept of sensory issues in autism, by giving a brief description of the above differences, and some examples of how these might impact on people.





Intensity

Sometimes my senses might work too well (hypersensitive) or not well enough (hyposensitive).

Hypersensitive means the channel is too open; as a result too much information gets in for my brain to handle.

Light touch feels like a cattle prod (Grandin)

I was also frightened of the vacuum cleaner, the food mixer and the liquidiser because they sounded about five times as loud as they actually were. (White).

Hyposensitive means the channel is not open enough; as a result not enough information gets in and my brain is deprived.

Sometimes their senses may become dull to the point that they cannot clearly see or hear the world around them, or even feel their own body. (Hawthorne)

When my senses are hyper I might do these things to stop the pain or calm myself down:

I might do these things...	Because
Rock Swing Hit my ears Press my eyes Twist Flap Spin	These can cause sensations which help my brain block out something I can't tolerate.

When my senses are hypo I might do these things to arouse my nervous system and get my senses working better:

I might do these things...	Because
<ul style="list-style-type: none">• Bang objects/doors• Seek out noises – Hoover, lawn mower• Prefer tight clothing• Self injure	These can cause sensations which help my brain get more information in from outside.





Sensory sensitivities – things to look out for:

Hypersensitive	Hyposensitive
<ul style="list-style-type: none">• dislikes dark and bright lights• looks at minute particles, picks up smallest pieces of dust• covers ears• dislikes having their haircut• resists touch• avoids people• runs from smells• moves away from people• craves certain foods• uses tip of tongue for tasting• places body in strange positions• turns whole body to look at something• difficulty walking on uneven surfaces• becomes anxious or distressed when feet leave the ground	<ul style="list-style-type: none">• moves fingers or objects in front of the eyes• fascinated with reflections, brightly coloured objects• makes loud rhythmic noises• likes vibration• likes pressure, tight clothes• enjoys rough and tumble play• smells self, people and objects• seeks strong odours• mouths and licks objects• eats anything• rocks back and forth• lack of awareness of body position in space• spins, runs round and round• bumps into objects and people





Sensory Overload

Sensory overload happens when there is too much information coming in at once and this is overwhelming. It can be very difficult for me to cope with. My brain might not be able to filter out anything irrelevant such as background noise, wallpaper, the feel of my clothes on my skin or people moving around. This means I have to try and process everything at once rather than just what is relevant at the time. Donna Williams (1994) describes this as having no sieve in her brain to help her select information that is worth being attended to.

Someone vulnerable to sensory overload needs to be in control of their environment. Learning to recognize early signs of coming sensory overload is very important. It is better to prevent it than deal with the consequences.

The sharp sounds and bright lights were more than enough to overload my senses. My head would feel tight, my stomach would churn and my pulse would run my heart ragged until I found a safety zone. (Willey)

Sensory overload has also been described as the 'eight ball theory' (Dena Gitlitz, 1999). Eight ball is similar to a juggler that can successfully juggle seven balls but if you throw in one more they will drop them all. Dena has a limited capacity for how many balls she can juggle successfully. This could be called the rule of the last drop – if a persons 'inner cup' is full already (whatever the reasons for this may be) the slightest trigger (which on days when the 'inner cup' is empty would not be noticed by the person) might produce a sensory overload.

The sensory overload caused by bright lights, fluorescent lights, colours and patterns makes the body react as if being attacked or bombarded, resulting in such physical symptoms as headaches, anxiety, panic attacks or aggression. (Williams)

In order to avoid sensory overload, autistic people acquire voluntary and involuntary coping strategies:

I might do these things....	Because...
Mono process (utilise only one sense at a time) Avoid direct perception of the stimuli Withdraw or remove myself Engage in a ritual or routine	These can reduce the feeling of being overwhelmed and cut out some of the sources of aversion, enabling me to recover.

Sensory Overload – things to look out for:

- Sudden outbursts of self injury or distress
- Tires very easily, especially when in noisy/bright places, or when standing
- Gets nauseated or vomits from excessive movement
- Withdrawal





Gestalt Perception

This is the inability to filter foreground and background information, so everything is perceived as a 'whole' rather than a combination of different items. This can happen in any of the senses – someone who experiences visual gestalt has difficulty focusing on a single detail of a scene and finds it almost impossible to separate it from the whole picture. If you are asking me to look at a photo or picture symbol, I might not be able to isolate the detail and will be looking as much at your hand/my hand, the floor below (anything else in my field of vision).

It was like having a brain with no sieve... (Williams)

Someone with gestalt perception will have difficulty if one slight detail is changed. For example, if a picture on the wall is not straight or a piece of furniture has been moved this changes the gestalt of the whole scene and the environment will feel unfamiliar. This can cause fear, stress and frustration.

This is also why I might have difficulty if one part of my routine is upset or changed, as I have an expectation of what it should be like and what should happen next.

Sometimes small changes are much harder to manage than big ones. If the order my CD's are stored in is changed, I will find this difficult. However, if I go somewhere I have never been before (like on holiday) this could be ok as I have no memory stored in my brain of how I expect it to be.

Moments with their own uniqueness challenged me so much that I began to fear all those unknown paths, clothes, food, shoes, chairs and strange human voices. Each one challenged me by putting in front of me a new situation for me to face and understand. (Mukchopadhyay).

These are things I might have trouble with:

- Ability to filter out visual stimuli
- Ability to screen out background noise
- Ability to distinguish between tactile stimuli of a different intensity
- Ability to distinguish between strong and weak smells or tastes
- Ability to co-ordinate body position and movement of body parts
- Ability to distinguish between inner and outer movements or sensations.

Gestalt perception – things to look out for:

- Notices every tiny change in the environment
- Easily frustrated if trying to do something in a noisy, crowded room
- Clumsy, moves stiffly
- Does not seem to understand instructions if more than one person is talking





Fragmented Perception

When too much information needs to be processed at the same time, people with autism may not be able to break down the whole picture into meaningful units. We might process some parts of a whole, for example parts of a scene or a sentence.

My ability to interpret what I saw was impaired because I took each fragment in without understanding its meaning in the context of its surroundings... I'd see the nostril but lose the concept of the nose, see the nose but lose the face, see the fingernail but lose the finger. (Williams)

Brad Rand, a person with autism, suggests that one of the possible causes for seeing things as disconnected might be lacking the facility to process all the relevant parts of something at once. This could result in overly narrow focussing of attention or insufficient memory resources to handle the task.

Everything seems to be conceptually separate and unrelated entities; 'on' and 'next' and 'in front of' don't mean much anymore, because whatever something is 'on', 'next to' or 'in front of' no longer has a reality until it itself is focussed upon directly. (Williams)

Fragmented perception means I might have difficulty dealing with people – because a person may appear as a lot of unconnected parts, each one of which is unpredictable. The strategy to cope with the problem is to avoid people and never look at them. It does not mean I can't see an entire person, but I may be unable to process the meaning of an entire person and process them bit by bit instead. As a result the mental image of a collection of bits is often meaningless and often frightening.

Fragmentation can complicate the way I interpret facial expressions and body language, hindering or blocking my interpretation of non-verbal communication.

I did not see whole – I saw hair, I saw eyes, nose, mouth, chin... Not face (Alex in Williams)



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I might experience fragmentation as frightening or confusing. These are some coping strategies I might use to help:

I might do these things	Because
Focus on a particular object or sensation – e.g.: My own breathing Tearing paper Arranging furniture Rubbing my fingers or hands together	Concentrating on one thing only cuts down the amount of processing my brain has to do which reduces the problem.
Physical activities e.g.: Running Bouncing	This can increase endorphins in my brain which help calm down the over stimulation and make it easier for me to deal with.
Get away from whatever is causing me problems e.g.: Shut my eyes Block my ears Remove myself from the source by leaving a room or people	Avoiding the source can help me recover and prevent the situation from escalating.

Fragmented perception – things to look out for:

- Resists any change
- Gets lost easily
- Does not recognise people in unfamiliar clothes
- Hears a few words instead of the whole sentence
- Selects for attention minor aspects of objects in the environment instead of the whole scene
- Complains about some parts of clothes, smells of some pieces of food etc.
- Complains about limbs or other parts of the body





Delayed processing

Sometimes it may take me a long time to process information that's coming in. This makes it hard for me to understand and learn new things. If I can concentrate properly, am feeling well and there is not very much distraction around I can cope better. It might not take much to distract me (people moving around, background noise, scratchy clothing...)

As a child it appeared as though I didn't feel pain or discomfort, didn't want help, didn't know what I was saying, didn't listen or didn't watch. By the time some of these sensations, responses or comprehensions were decoded and processed for meaning and personal significance, and I'd accessed the means of responding, I was fifteen minutes, one day, a week, a month, even a year away from the context in which the experiences happened. (Williams)

Processing can become delayed if there is too much information coming at once, e.g. sensory overload. It might take me longer to process and understand what I am seeing/hearing/feeling, and respond to it. This process is described well by VanDalen:

When I am confronted with a hammer, I am initially not confronted with a hammer at all but solely with a number of unrelated parts: I notice a cubical piece of iron within its neighbourhood a coincidental bar-like piece of wood. After that, I am struck by the coincidental nature of the iron and the wooden thing resulting in the unifying perception of a hammerlike configuration. The name 'hammer' is not immediately within reach but appears when the configuration has been sufficiently stabilised over time. Finally, the use of a tool becomes clear when I realise that this perceptual configuration, known as 'hammer', can be used to do carpenters work.

This is a good example of delayed processing. Imagine if you were given a hammer and had to break down the process each time to understand what it is and what it can be used for. You do go through this process, but it all happens in a split second automatically, without a second thought.

In addition, delayed processing can make it hard to learn things in the right context. If I learn the skill of making a cup of tea in the kitchen, I might not be able to transfer this to a different kitchen, or a different person supporting me and will have to start learning it again.

Delayed processing – things to look out for:

- Delayed responses to stimuli
- Poor at sports
- Oblivious to risks
- Any experiences are perceived as new and unfamiliar, regardless of the number of times the person has experienced the same thing





Distorted perception

Sometimes, my senses get distorted, which means they may change or misrepresent what I can really see, hear, touch, taste or smell.

I used to hate small shops because my eyesight used to make them look as if they were even smaller than they actually were (White and White)

I had no sense of my body from the waist down, it felt like I was flying. (Oliver in Williams).

Distorted perception is reported to become worse in the state of information overload. When my senses are distorted, I may understand things differently – here are some things I might have difficulty with:

- Space expands or decreases
- Changes in shapes and sizes
- Can't associate the location, form and texture of objects
- Fears of heights, stairs and escalators
- Double vision
- Seeing everything in two dimensions only
- Poor awareness of my own body
- Unable to distinguish between some sounds.

Distorted perception – things to look out for:

- Fears heights and stairs
- Has difficulty catching balls
- Appears startled when being approached
- Compulsive repetitive hand, head or body movements
- Hits eyes, ears, nose





Sensory Shutdowns

Shutdowns happen when someone can't deal with all the information coming in – for example if they are experiencing a sensory overload. All or some of the senses are being overloaded and the person is unable to cope. Often we manage by shutting down one or some of our sensory systems – to block out the stimuli coming in and enable our other senses to function better:

Auditory and tactile input often overwhelmed me. Loud noise hurt my ears. When noise and sensory stimulation became too intense, I was able to shut off my hearing and retreat into my own world. (Grandin)

Sometimes I might need to shutdown my sense of hearing. If this happens, you might think I am behaving as though I am deaf. This can sometimes make people think I am ignoring them or being rude.

I might do these things...	Because....
Shut down one or some of my sensory channels Withdraw Avoid Engage in a routine or ritual	This can reduce the incoming information and help me cope with it better.

Sensory shutdowns – things to look out for:

- Sometimes does not react to any stimuli
- Seems not to know how to move own body
- Disoriented in noisy/bright places
- Rocks unconsciously during other activities





Compensation

Because of sensory sensitivities/fragmented or distorted perception or delayed processing, a person may compensate through other more reliable senses to build a better understanding of their environment.

To many autistic people, the senses of touch and smell are more reliable. Many autistic children touch and smell things. Some constantly tap everything to 'see' the boundaries in their environment, like a blind person tapping with a cane. (Grandin)

Therese Joliffe preferred using touch to learn about her environment and get a relatively accurate representation of the world. Because her senses of hearing and vision were disturbed and gave her unreliable information she 'saw' the world through her fingers.

I might do these things....	Because...
Smell, lick, touch or tap objects Look for the source of a sound Inspect food before eating it Watch my feet whilst walking Watch my hands whilst doing something Avoid walking on uneven ground	I need to use other sensory systems to give me reliable information about my environment so I can make sense of it.





Good practice guidelines for supporting me...

Many autistic authors have written about how they experience the environment (including other people) and how this makes them feel. The list below gives some ideas of what can be helpful or challenging for a person on the autism spectrum. Some things on the lists might be relevant to me and help me feel less stressed.

These things might help me...	These things might challenge me...
Look to the side of my face or over my shoulder when you are interacting with me	Direct eye contact
Address what you are saying to the wall	Direct communication
One person talking to me at a time	More than one person talking to me, other peoples conversations
Neutral odours	Perfume, aftershave or other scents
Plain clothes	Patterned clothing
Dull coloured clothing	Bright coloured clothing
Uplighters	Strip lights
Red or green bulbs	Bright or white light, bright sunshine
A quiet environment	Kettles, engines, traffic sounds, phones
Quiet personal care	The toilet flushing, running water, fans
Consistency	Different people responding to me in different ways
One thing at a time	Being bombarded by a lot of information
Knowing what is happening next	Unpredictability and chaos

If you try using some of these ideas and avoiding things which could challenge me, through observation you should be able to tell if any are relevant for me. But sometimes just the fear that something *might* happen is enough to make me feel stressed. For example, if I have a problem with the noise of the toilet flushing, and you stop doing this, it might take me a long time to feel confident that when I have my personal care the toilet is not going to make that noise. The fear that it *might* happen can be as bad as it actually happening.

Most people with autism are 'monotropic'. This means we can only utilise one sense at a time. You are 'polytropic' because you can see, hear, feel, smell and taste all at the same time. You can even talk to another person while you are doing all this!



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So if I am looking at something, and you speak to me, it might appear that I don't 'hear' you. There is nothing wrong with my ears, but my brain won't process what is coming in if it is busy processing what I am seeing. If you want me to look at something and listen to you all at once, I might not be able to do this and I could feel 'overloaded' by these demands. This could make me feel stressed and I am limited in how I can address this:

If I'm looking at something and listening to something at the same time, too much information might come in my eyes and ears at the same time, so I might touch something. That gets information going in a different sense, through my touch, and it lets my eyes and ears have a rest. (Rand)

Generally, existing and surviving in your world can be very tiring and stressful. For many people on the autism spectrum, it is a huge effort just to 'be'. And this is why having periods of 'low demand' or chill out time can be helpful, as can following a routine or ritual. These things need to happen so we can regain our composure.

There are many things that people with autism often seek to avoid: external control, disorder, chaos, noise, bright light, touch, involvement, being affected emotionally, being looked at or made to look. Unfortunately many educational environments are all about the very things that are the strongest sources of aversion.

Donna Williams

Please remember I might have different sensory perceptions to you and be aware of this at all times when working with me, especially if there are situations when I am upset or distressed and you don't understand why.





Conclusion

We hope the information in this booklet has been interesting and relevant to your work. We know there are no easy answers in autism, but being aware of different aspects of autism and how they can affect people is a big help. Sensory issues can be one explanation for challenging behaviour, and this should not be overlooked. Even if we can't 'fix' everything, having a better understanding of how an autistic person experiences the world can help us accept some of the challenging situations we encounter. This can go a long way towards developing positive relationships, which are a big factor for wellbeing and quality of life.

If you support people on the autism spectrum and understand a bit about this you might begin to notice possible sensory issues for people, or think differently about some of the triggers for behaviours. The more we learn, understand and experience the better placed we are to provide the right support for people with autism.

At times our very state as autistic individuals seems to threaten the neuro-typical (non-autistic) world because we show you up for who you really are. Please don't be part of the 'us' and 'them' syndrome. Don't succumb to ignorance and typical thinking. Take the time to get to know 'autism'. Take the time to get to know us. (Lawson)

If you wish to find out more, the books listed on the next page are available for loan. Members of the Autism and Practice group have a good knowledge in this area and are happy to be contacted if you have any questions.

Thank you and good luck!

The Autism and Practice group
Learning Disability Services

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Autism and sensory differences – Recommended reading

Title	Author
<i>Sensory Perceptual Issues in Autism and Asperger Syndrome</i>	Olga Bogdashina 2003
<i>Asperger's Syndrome</i>	Tony Attwood 1998
<i>Autism and Sensing: The Unlost Instinct</i>	Donna Williams 1998
<i>Finding You Finding Me</i>	Phoebe Caldwell 2005
<i>Asperger Syndrome, the Universe and Everything</i>	Kenneth Hall 2001
<i>Behavioural Concerns & Autistic Spectrum Disorders</i>	John Clements & Ewa Zarkowska 2000
<i>Through the Eyes of Aliens</i>	Jasmine Lee O'Niell 1999
<i>University Course Materials</i>	Olga Bogdashina 2005
<i>Understanding and working with the spectrum of Autism</i>	Wendy Lawson 2001
<i>Autism: Explaining the enigma</i>	Uta Frith 2003

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