



We are an information and advisory service for people with Autism Spectrum Disorders, their families, whanau and the wider New Zealand community

Summer 2013

# Journal

## Introduction



**H**appy New Year to you all and welcome to our Summer publication of the Altogether Autism Journal. As usual with our Journal we have a theme and this edition focuses on Sensory Issues. We hope that you enjoy reading the articles and the stories that people have kindly shared as well as finding some of the suggested strategies useful.

**\*\*STOP PRESS\*\*** We are excited to announce that Altogether Autism will be holding its first ever conference at the Kingsgate Hotel, Hamilton on July 9<sup>th</sup> & 10<sup>th</sup> of this year. The title of our conference is, 'Inspiring Excellence in Autism' – highlighting and encouraging research, best practice, worthwhile support and effective self advocacy in New Zealand. Keynote speakers include, Professor John Werry, Consultant Clinical Psychologist Tanya Breen, Dr David Newman and Dr Matt Eggleston. The conference content will appeal to ALL with an interest in ASD, whether you are a person with autism, a parent who has a child or a family/whanau member with autism or you are a professional seeking professional development. Keep an eye out for updates with further information and details.

All of us at Altogether Autism wish you a healthy and happy 2013 and we very much look forward to meeting you at our upcoming conference in July. **Paula Gardner (National Manager)**

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## Living with Sensory Sensitivities - A Personal Account

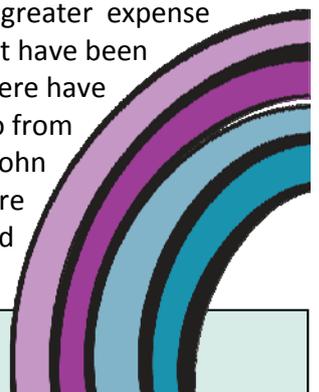
**J**ohn Greally spoke to Altogether Autism about his particular sensory issues and how he has learned to manage them over his life. He emphasized that sensory issues are not a condition of the senses (the skin, eyes, ears, sense of smell) but of the way the brain processes the information received from the senses. Consequently he still experiences sensory issues as intensely as he ever has, but has become more adept at managing them. This has reduced the impact they now have on his life.

John's particular sensitivities relate to his eyes and his skin. He recalled that from an early age he loved sitting in the sun and would do so with one eye closed and his head tilted to shade the other eye, a practice that led to him developing a lazy eye. As he got older, John

learned to stay indoors to avoid the discomfort of the sun that he loves.

As an adult, an optometrist assisted him to select glasses to reduce his sensitivity to sun; frameless polarized light weight acrylic lenses with a photosensitive film and anti-glare for night driving, with titanium arms, hypoallergenic nose rests and clip-ons. They come at a far greater expense than his previous spectacles but have been a boost to coping with light. There have been psychological benefits too from investing in the new glasses. John found that he felt more confident and experienced

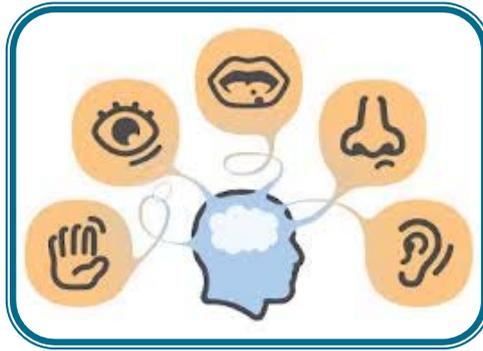
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## Living with Sensory Sensitivities - A Personal Account Continued...

From page 1... greater mental clarity from the shaded aspect of his glasses reducing the amount of information he needs to process so feels more 'present'. The automatic darkening of the glasses creates a shield which reduces the stress he can experience from eye contact with others.



Skin sensitivity has also been a lifelong issue for John to manage, with fabrics against his skin a constant source of irritation. As a child he discarded many clothing items in his search for soft, cushioned fabrics. A beach toweling jacket became a favourite summer and winter garment for four of his early teenage years. Favourite garments had to be relinquished for church each Sunday when the woollen jersey his mother required him to wear was discarded with relief after the service. The scratchiness of his woollen blankets was only redeemed by the silkiness of the satin edging around his face.

There was the battle of the shoes as well. For his mother, to have one of her 10 children barefoot was a bad look whatever other concerns she had for the protection of her son's feet. By removing his shoes once out of eye-shot, John could make his shoes last two years compared to the one year of other children. When they fit well and were dry he found them nice to wear. Unfortunately, John shared the same propensity that young men on the ASD spectrum often experience of susceptibility to fungal infections. The anxiety that men on the spectrum experience affects the moisture in the feet and therefore shoes. Having his feet slipping around in a pool of moisture was very uncomfortable. He has since worked out the most effective methods and products to keep shoes dry.

John also found that shoes affected his balance, as he was prone to clumsiness, shoes made that worse. John completely discarded shoes for a number of years as an adult living in Wellington and was barefoot through a number of harsh Wellington winters. The better connection, that being barefoot gave him, between the earth and his feet helped with his balance (thus assisting his proprioceptive senses which let us know where a body part is and how it is moving). John mentioned the particular importance of pressure information from

the big toes to letting you know where you are in space.

Cotton clothing was an ongoing battle for John. If it was new, the starch in the fabric irritated. And well washed cotton, although softer, contained lime build-ups that also irritated. John became a bit of an expert on how to keep the washing soft and fluffy. But it was a

chance buy of a shirt from a recycled clothing store that revolutionized his clothing. The shirt he selected felt softer than cotton. He later found out that was made from polynosic – a fabric made from strands of the beech tree. Lime-scale does not attach itself to the fibre of the fabric, so there is no irritating build-up. Polynosic (also known as Model) doesn't need ironing, which John says is an added bonus for Aspie males. He now has a collection of polynosic shirts but has found it much harder to buy pants and jackets in the fabric.

John's sensory issues have from time to time created sensory overload for him. As a child he managed this by withdrawing into himself and by daydreaming, creating a world re-ordered to suit himself better. Nowadays, he tends to deal with sensory overload by getting into a set of oversized loose clothes, nice and baggy so that only 50% of the fabric touches his body at any one time. After a few days, he finds that he can switch back to normal attire. He also finds that immersing himself in his special interest helps distract him during those times that he is feeling especially sensitive.

Fortunately for John, and the ASD community, his special interest is ASD and he is generous in the time and support that he gives not only to others on the spectrum, but to others involved in the ASD community. He believes that his own experience of sensory issues has enabled him to anticipate what may be affecting his son, and others who seek his support. Often people can be unaware of what is getting to them and he enjoys helping to break down what is going on for them and giving them solutions. John appreciates that having his own sensory experiences enables him to assist others. He clearly has learned a lot about sensory issues and has many tips and well researched information to pass on.



## What are Sensory Processing Problems?

Sensory processing disorders (SPD) is an emerging and currently contentious field; having it's proponents for it to be a stand alone disorder, and those who do not believe it is a real diagnostic entity. There are pediatric neurologists who regard sensory issues as a nonspecific indicator of neurodevelopmental immaturity and not as a sign of a distinct disorder at all.

The Sensory Processing Disorder Foundation campaigned vigorously for inclusion of the disorder in the forthcoming edition of the DSM-V, due out in mid 2013. The Foundation accepts that it won't be a separate diagnostic category and, consistent with other sources consulted by Altogether Autism, acknowledges that a sparse research base exists.

A problem in trying to establish a good research basis for the disorder arises from sensory processing issues often being co-morbid with other conditions; autism; developmental delay; intellectual disability; OCD; anxiety; Down Syndrome; Fragile X; ADHD and others.



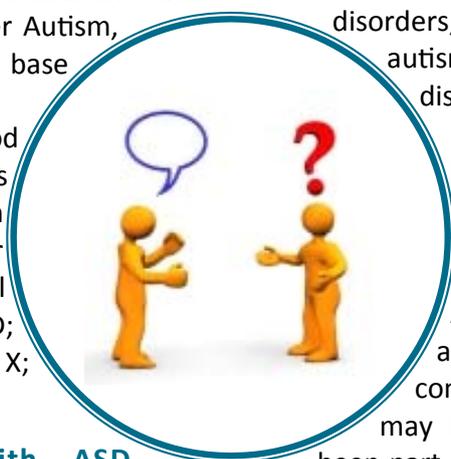
## Are people with ASD more likely to have SPD?

Sensory issues are a very common and well established condition for many people on the autism spectrum. The relationship between sensory symptoms and autism was investigated by Kern and others in 2007. They found that sensory problems correlate with severity of autism in children but not in adolescents and adults. This finding may be the result of maturation or may be attributed to the questionnaire that was used in the research (the Sensory Profile). In assessing children it relies on parent/caregivers perception whilst the adult and adolescent versions require self-report. There may be differences in how others perceive someone's sensory difficulties and how the person themselves experiences them. Or it could be that as people get older they find ways to try and manage their sensory issues and so don't experience them with quite the severity that they did when they were younger.

## Some people want Sensory Processing to be a diagnostic criterion for the new DSM-V. What's happening with that?



Sensory Processing Disorder may be included in the DSM-V as a novel diagnosis in need of research. It is likely that the sub-category of Sensory Over-Responsivity will be included as one of several criteria for ASD, in recognition of how common sensory issues are in autism. The Kern study (2007) examining the relationship between sensory dysfunction and autism found that sensory dysfunction is global in nature and sensory processing problems need to be considered as part of the disorder. It is worth noting that although sensory processing disorder commonly exists with autism spectrum disorders, sensory symptoms don't differentiate autism from other developmental disorders.

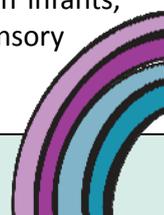


## How are Sensory Processing issues assessed?



Altogether Autism was unable to find any diagnostic tests for autism that contain scales for sensory issues. This may be because sensory issues have not been part of the diagnostic criteria for autism. It will be interesting to see if the commonly used diagnostic scales for ASD in the future include sensory scales, if sensory disturbance does indeed make its way onto the list of diagnostic criteria for ASD in the DSM-V. Assessing sensory issues in autism currently requires separate assessment tools.

The most commonly used measure from the research appears to be the **Sensory Profile**. This is a useful standardised tool that measures sensory abilities and their effect on functional performance. It's a judgment-based questionnaire which compares a child's responses to visual, touch, taste, movement, and multi-sensory stimuli against a normative sample of children. A strong pattern of over or under-responding can be determined and the areas in which those responses most often occur. The instrument also has profiles for assessing sensory issues in infants, adolescents, adults and for assessing sensory issues in the school setting





## Question and Answers on Sensory Issues Continued...

The other popular assessment tool is the **Sensory Processing Measure**. This instrument is very similar to, and gives the same information as the Sensory Profile but is shorter and quicker to use, however, it can only be used for school age children between 5 and 12 years of age. It has a number of different forms which enables sensory issues to be assessed in the home and at school, both in the classroom and in specialized environments such as at art, music, PE, interval, the cafeteria and on the bus.

Although other evaluation tools do exist for assessing sensory function in children: the **Test of Sensory Function in Infants**, the **Peabody Developmental Motor Scales 2<sup>nd</sup> Ed (PDMS-2)**; and the **Bruininks-Oseretsky Test of Motor Performance (TMP)**, none of these instruments are as psychometrically robust as the Sensory Profile.



**What assessment tools are used in New Zealand?**

The Sensory Profile and the Sensory Processing Measure appear to be the most commonly used instruments in NZ. Practitioners that Altogether Autism consulted commented that the greatest value in assessing sensory issues comes from understanding the impact that it has on the functioning of the person with autism.

In NZ, sensory issues are most likely to be assessed by a psychologist or an occupational therapist. Practitioners stressed that sensory issues should not be assessed only with a measurement tool but also involve clinical observation and interviews.

**How can I help Altogether Autism build up more information on Sensory Assessment?**



Altogether Autism would love to hear from practitioners who use other assessment tools and from people on the ASD spectrum who have had other assessment measures used to assess their sensory issues. We would also like to hear from you about how having an assessment of your sensory issues benefitted you.

### Reference

Autism: the International Journal of Research and Practice (2007) March, Vol. 11 (2), PP. 123-34

Kern JK, Trvedi MH, Grannemann BD, Garver CR, Johnson DG, Andrews AA, Salva JS, Mehta JA, Schroeder JL.

[www.goo.gl/FJ3ZY](http://www.goo.gl/FJ3ZY)

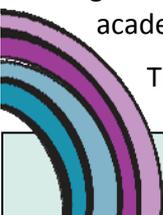
## Managing Sensory Issues in the Classroom

**S**chools hold the best intentions for their students and reflect these in such aspirational statements as 'every child is a star!' The aspirations of schools fall broadly into statements that reflect the uniqueness of children, providing positive learning experiences and empowered connected learners, positive relationships based on respect for self and others and enshrining the rights of every child to quality education in safe and secure school environments. These aspirations apply also to pupils on the autism spectrum who have their own challenges in trying to attain educational outcomes at school. Sensory issues such as auditory focusing difficulties, sensory under-responsiveness and sensory seeking has been found to be associated with academic underachievement.

Therefore, in order to minimize the

difficulties that occur later on for children with ASD with sensory difficulties; educationally, socially and personally (their self-esteem and self-confidence) it is important to address any sensory problems they have in the classroom. With the majority of children with ASD experiencing sensory difficulties, a teacher who has a child with ASD in their classroom is highly likely to need to assist them with their sensory challenges. Sensory problems are best detected before a child is seven, in order for him or her to get the best out of an intervention and their education. Some believe this is due to their nervous system still being malleable, others because children haven't yet learned to make adaptations which may mask underlying symptoms.

Parents can help teachers by making them aware of sensory problems that occur for their child and sharing solutions. **Continued on page 6...**



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**M**y son Brodie is 11 years old and was diagnosed with mild autism at 17 months old. The diagnosis over the years has been upgraded to moderate classic autism with severe sensory issues. When Brodie was little, no-one appeared to exist and he lived in his own world, a lonely world with nothing to do. With a lot of hard work and perseverance he started to acknowledge the world around him and with the joy of having my child start to see the world he lived in came the horrors of how much the world hurt him because his sensory issues were so bad. He just couldn't cope and would self harm and hit out at both myself and his grandmother. I could probably write a book from a parent's perspective on it as it has and still continues to rule our lives. Light, noise, and people – it was like a form of torture for him as the years rolled by and he couldn't fit in anywhere. My son could hear a weed eater miles away and would be in full meltdown until the person stopped using it.

Kindy was a dreadful experience and with regards to school I fought like mad after the first two years to have the right for him not to be made to be included (it's everyone's right to be included but some people just can't cope with it). Brodie is off to college next year and hasn't been mainstreamed for two years as I have found with some educational places, it's all or nothing. He will be in a unit and is really looking forward to being with others but in a smaller, quieter environment. Brodie's mental and emotional well being has always been top of my list and although at times over the years, I have had to 'build a bridge and get over it' there have been times when the wood pile has run very low. How I have gotten through is that once some comprehension came along (around age 8 and that's when he started speaking a little also) I was able to start a reward system. With so little of interest to him it was so hard but I found something and became very creative as he got bored easily with them. Luckily now he has a counting money box and I am teaching him to save for what he wants to buy. He has a safe bedroom which is now carpeted to lessen

the damage he can do to himself and the room – getting him there is often a challenge because he is a tall and heavy young man.

The worst triggers were having a shower (it hurts his skin) and going to kindy/school. Words were foreign to him and Picture Exchange Communication System (PECS) didn't register. We had to make sure he had every type of visual available (I've gotten creative with them too) and for pictures it had to be the actual place or thing. Desensitization has never worked, no matter how many times or months or years you persevere so until he had better comprehension, we just didn't go anywhere much and became very isolated. With the recent diagnosis of chronic fatigue and fibromyalgia we have been using Clonidine patches with some great success, while it doesn't cure his anxiety it makes him able to try new things or go places without having an almighty meltdown as soon as we leave somewhere.

Having a nutritious diet is non-existent, it's mainly salt & vinegar chippies and hot chips – with the patches I have been able to introduce some small amounts of salad items but meat is a no-no. Brodie told me that his family eats 'dirt and mud' because that's what it is to him, it's the taste, texture and smell that grosses him out and that goes for any oral medication also. We can't use public transport and he

doesn't feel safe out of his home no matter how much I make it out to be a great experience. He really trusts me but when he looks at me sometimes it's as if he is saying to me 'why can't you make me better'. I find it mentally exhausting sometimes trying to figure out how I could make things better for Brodie, trying to anticipate what might happen at any given time and juggling to keep everything as calm and happy as possible. I'm a pretty strong person but I have to admit without my mother I would not have coped, she continues to be my wonderful emotional support. I love my son so much and I will always try to make the world a better place for him where I can.

**By Tracy Collis**





## Managing Sensory Issues in the Classroom Continued...

Continued from page 4... But if that information hasn't been passed on, how can a teacher know if a child is experiencing sensory problems? Symptoms in pupils can be easily misinterpreted as psychological problems or bad behaviour and a meltdown resulting from sensory overload can certainly present as a 'tantrum'. This often isn't easy as sensory issues don't fit tidily into a discrete category. Knowing the context helps to distinguish.

Sue Larkey runs a website on matters relating to ASD.



Sue Larkey

She provides an example of behaviour meltdown in a child because he arrived at school and found his desk was moved by the relief teacher. His melt-down being prompted by anxiety over the unexpected changes. This requires a different solution to a melt-down occurring when he arrived at school and children were playing

recorders in the class, at which he covered his ears, screamed and ran away. Altogether Autism is always willing to provide information on sensory issues as they may present in a school setting and what teachers can do to assist.

Lisa Palmer, Occupational Therapist with the Ministry of Education was asked when and where to get help for pupils with sensory problems. Lisa outlined a useful process that teachers can go through in trying to address a sensory problem. Start by identifying the behaviour that is problematic and do some measurement about it (how often is it happening, in what contexts etc.) Whatever you decide to try, apply appropriately so that you give it the best chance to work. Don't persevere if it doesn't. Expect that different strategies work for a while and that you may need to find something else. Communicating with the parents about what's being tried at home and school (home/school diaries or notes in the lunchbox) can be helpful.

Teachers can speak with the Lead Worker from MOE and/or their Service Manager. Schools know who those people are for their

district. It's time to call in a specialist when a teacher is finding whatever they have tried is not working or an RTLB has been involved but the behaviour is still

problematic. It may also be time to get a specialist involved if the child is calmer but is not attending any better. Specialist intervention at that point would be aimed at trying to shift the child to the next level so they can engage with their learning.

Accessing an MOE occupational therapist is done through ORS funding or through the physical disability service. Any assessment would be conducted at the school. Lisa said she aims to visit two or three times with the intention of observing the child at different times of the day and over different activities and environments. She interviews teachers and parents and undertakes formal testing. A formal assessment would only occur if there is a pattern of behaviours or repeated behaviours, out of context to the child's peers, which impedes the child's learning.

So regarding sensory difficulties that occur in the classroom setting for children on the autism spectrum, there is much that teachers can do using readily available information and resources. Altogether Autism is always happy to respond to information requests on the researched effectiveness of approaches, in order to help teachers make informed decisions regarding interventions they are considering using.



### References

American Journal of Occupational Therapy. American Occupational Therapy Association, Incorporated

Ashburner J., Ziviani J., Rodger S. (2008) Sensory processing and classroom emotional, behavioral and educational outcomes in children with autism spectrum disorder.

[www.suelarkey.co.nz](http://www.suelarkey.co.nz)

**How a child may act at school if he or she has proprioceptive difficulties... the sense of ones' own body in relation to itself and things around it.**

**If a child is under-responsive, their behaviours will be sensory seeking.**

**Some examples:**

- Doing things too hard... walking, pushing, banging, in the way they play with objects
- Have insatiable energy... be loud, rough, crash into things
- May show in how they treat their body... knuckle cracking, chewing their fingers, biting their nails until they bleed
- Wear their clothes tight... turtle necks, keep zips on jumpers/jackets done all the way up, wear their belts tight

**If a child has poor body awareness and motor control, he or she may show it through:**

- Poor coordination... with climbing, running, biking, ball skills etc.
- Can't tie shoe laces
- Bumping into things
- Tripping and falling
- Have problems with stairs

**Postural instability may be demonstrated by:**

- Appearing limp and lethargic
- Slumping at the desk
- Needing to rest their head on their hands when working at a desk
- Find it hard to do balancing tasks

**To help a student with sensory difficulties, teachers can make changes to the environment, to materials, activities or the way they give instructions.**

**Here are some suggestions:**

- Seat a child who is light sensitive, away from windows
- Seat a child who is noise sensitive away from the door or hallway noise
- Make a quiet, non-visually stimulating area for the student to work at so he or she can concentrate
- Providing a rocking chair or beanbag can help with calming
- For students with visual challenges, use larger print on the page to stop words flowing into one another
- Let the student do their work on a computer, if handwriting is too difficult for them or their writing illegible
- For students with auditory sensitivity, provide earphones or ear plugs to block out disturbing sounds. Other students may need to wear headphones that have white noise so that they can concentrate without having to filter out unnecessary and annoying sounds
- To avoid additional anxiety, give the student prior warning that they will be called upon to speak in class

**Occupational Therapists who work for the Ministry of Education have skills and knowledge in:**

- Occupational therapy theory and practice
- Child and human development
- Skills in managing assistive equipment and technology in a variety of settings
- Knowledge of sensory, motor and cognitive development
- Knowledge of community and family support services

**Ministry of Education website [www.minedu.govt.nz](http://www.minedu.govt.nz)**



We are an information and advisory service for people with Autism Spectrum Disorders, their families, whanau and the wider New Zealand community



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