



Sensory Integration Disorder

Sensory Integration Disorder (also known as Sensory Integration Dysfunction, or SID) occurs when the brain is unable to appropriately integrate the signals it is receiving from one of the senses. This can lead to unexpected responses from various stimuli, either an over reaction, or an under reaction. Children with SID can't regulate their sensory input very well and tend to have a "fight or flight" response to sensory information, rather than being able to plan and organise a response appropriately and automatically. Factors that contribute to SID can include premature birth, learning disabilities, autism and other developmental disorders and ADHD.

The senses affected include not only the main five senses of sight, sound, smell, taste and touch, but also movement (the vestibular sense) and position in space (proprioception). Touch, or the tactile sense, seems to

be commonly affected. Children who dislike the tags on their clothes, the seams on their socks, being gently stroked, being hugged, touching different textures such as play dough, clay, dirt or sand can all have what is known as "tactile defensiveness". Other children crave touch and want to constantly be in contact with something or someone.

Children with SID ... tend to have a "fight or flight" response to sensory information

Children who will only eat bland foods, or spicy foods, or crunchy or smooth foods may be having trouble with their taste sense. The child who flinches from sounds that others are barely aware of may be having trouble integrating auditory signals, as is the child who likes everything LOUD.

Our vestibular sense helps us to move around and

changes in position can be difficult for the child whose sensory input is disordered. Children who are over stimulated by movement can find moving from one surface to another, such as from carpet to tiles, grass to concrete, quite difficult and changes in height such as steps can be very hard to deal with too. The child who is under stimulated by the vestibular input they receive may spend all their time moving around and love swinging and bouncing.

Proprioception helps us to know where we are and children affected this way may seem very clumsy and uncoordinated, as if they don't know where their body starts and ends. These children may have trouble just staying upright in a chair.

There is some dispute as to the validity of a diagnosis of SID. SID is not defined in either of the commonly used and accepted diagnostic manuals (DSM-IV or ICD-10) which means that some professionals do not accept it as a valid diagnosis. But regardless of whether your child gets a "label" of SID or not, if your child is having trouble, and it is affecting their (or your) day to day life, they need to be seen by someone to have their condition managed.

Kirsten Burkitt

The sources used for this article are listed on page 3

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From the Editor

Hi all

Well here we are with our second issue. My thanks goes out to you all for your feedback on the first issue and we were glad that it was warmly welcomed by you all.

I have enjoyed putting this newsletter together for you and have learnt so much.

Please do not hesitate to send us your ideas for newsletter topics and we look forward to your survey responses.

Catherine



From the President

It was great to get such positive feedback from the first edition of our Newsletter, I hope you enjoy this one too!

We have our AGM coming up in September, and I hope the many of you can attend. This is your opportunity to have a say in what goes on at Austprem. Nominations for various positions will be accepted prior to the AGM, with any necessary vote happening at the meeting.

If you have any questions about how it all works, please contact me or another member of the Committee, or just post a question to the Forum. There are further details on the AGM elsewhere in this issue.

The new look website went live earlier this month, so take the time to have a look around it - there are a number of useful resources there, and if you feel able to contribute a story, or a book or website recommendation, please let us know - a few hundred people visit the website each month, and many of our new members find their way to the Austprem mc2 Forum after looking around the website, so it is great to keep building it up as a resource.

Healthy end of winter wishes to you all!

Leanne

When to tell...

It can be a frightening and difficult time if and when you discover that your child's abilities are different to those of other children at pre-school or school. It can be very confusing when deciding who to tell and discuss these differences with.

Some people prefer to tell no-one and keep it in the family others choose to tell the world and others are a combination of these two extremes.

From an education perspective it is always best if your child's teacher knows. This may be extremely difficult to discuss with your child's teacher, and teachers understand that.

However so that your child's needs can be best met it is important to discuss any difficulties you may notice your child having. This can ensure that your child can get the best assistance possible.

In today's education climate of inclusion and integration your child's teacher will need as much information you can provide about your child's needs as possible. You as the parents are the most important

educators of your children, and will be in the best position to judge if and when they may need help.

Sometimes your child's differences are obvious as they may be physical and these can require modifications in classroom settings to assist your child to feel comfortable in his/her classroom. However, not all differences in abilities are obvious to the eye.

Teachers are not mind readers and also teachers are not the enemy.

**Teachers are not
mind readers**

Often teachers can come across that way, they don't mean to, and they also have your child's best interests at heart.

If the need should ever arise for you and your family remember, talk to the people who have a large involvement in your child's life. The more information they have the better the chances your child has at success.

Please remember that teacher's will do what they can but often they are also frustrated by the system, together however you can help each other to help your child.

Catherine Harding

Apologies

The article on Developmental Care has been held over - watch out for it in a future issue!

Austprem—Pregnancy Support Group

The Austprem – Pregnancy Support Group has been set up for those who are contemplating or experiencing a pregnancy following a preterm birth, and for those at risk of giving birth prematurely.

Whilst many pregnant mothers feel a little apprehensive, mothers who have previously delivered a premature baby, or who have been told they are at risk of doing so, often have concerns about their pregnancy. The Austprem – Pregnancy Support Group is a great group of people who understand what you are feeling. We know what it is like to consider another pregnancy, and the group

can support you as you try to make this important decision (we can't make the decision for you though!). For those that do go ahead with a pregnancy, support is provided throughout, celebrating with you as you reach milestones, sharing in your ups and downs and listening to your fears and hopes.

We hope that everyone can go on to deliver healthy full term babies, but we know that this isn't always going to happen. The Pregnancy Support Group is there to celebrate the birth of your baby, whenever you deliver.

Everyone is welcome to join Austprem – Pregnancy Support Group. You might be pregnant again, you might just be thinking about another pregnancy or you might have already completed a subsequent pregnancy and want to support someone else who is just starting on the journey. Sharing your thoughts and experiences might just help another mother, and support is what Austprem is about.

You can find information about joining Austprem – Pregnancy Support Group at <http://www.austprem.org.au/psg.html>

Further Reading

Journals:

Always check with your baby's doctor or other healthcare professional as to whether any practice or procedure you read or hear about is appropriate for you and your baby/child.

Sensory Integration Dysfunction is controversial dx

Carl Sherman

Family Practice News 10 (3)

Feb 2000 p40

Sensory Integration Disorder

Beth A. Kapes

in *The Gale Encyclopedia of Medicine* 2nd ed.

An introduction to : early childhood sensory integration

Carolyn O. Cantu

The Exceptional Parent 32 (4) April 2002 p47-51

Is Sensory Integration Dysfunction for real?

Letter by Sheldon T. Berkowitz

Reply from Martin Baren

Contemporary Pediatrics 17 (5) May 2000 p36

If you would like to access a copy of any of the journal articles listed here please contact kirsten@austprem.org.au



Michael (31 weeks) holds his newborn Full Term baby sister

In Loving Memory - Paul and James Thewlis

We are all very sad to learn of the tragic loss of Paul Thewlis and 6 year old son James who recently died in a house fire.

Paul and James were founding members of Austprem and featured in last month's newsletter article on kangaroo care.

Our heartfelt thoughts go out to Angela and Elizabeth.



Angela holding James with Elizabeth and Paul also touching him

Michael's Story

Michael was born at 31 weeks, weighing 1278g. He had a relatively smooth NICU course, he was ventilated for 5 days and had a grade I IVH. Michael suffered from reflux but has been generally healthy.

When Michael started eating, many people commented on what a neat eater he was, he didn't throw food around, or get it in his hair, he rarely even needed his face and hands wiped after a meal. I saw this tidiness in his play too, he avoided sand, water, grass and dirt. If he fell over, he was usually more upset about the dirt on his hands than the skinned knee!

Michael is allergic to cow's milk, and didn't start on soy products until after he was two years old, so he was probably about 2 ½ when I first suggested he try soy yoghurt. Michael was very excited to have yoghurt and sat down ready for it. I opened the lid, he looked at it, and ran, screaming. Thick and goopy is not a texture he likes. Michael had a similar reaction to playing with shaving cream.

Michael was nearly 3 ½ when I first heard the term "Sensory Integration Disorder" from his OT. She felt that Michael had particular problems with tactile defensiveness, as well as with his auditory sense. Michael has always been very upset by loud noises, or lots of noise.

At 3 ½, Michael wouldn't touch play dough, he gagged when I fed his little sister rice cereal (that thick and goopy texture again, and he wasn't even the one eating it!), he had trouble eating with a fork and/or spoon (another issue), but didn't like to touch his food either, he wouldn't paint (even with a paint brush). He wouldn't participate in many of the activities at Kinder, and the noise there disturbed him at times too. All in all, his SID issues were having a big impact on his life.

We worked on the play dough issue by me getting the play dough out and breaking it up into little bits and Michael telling me he didn't want to play. I would then tell him to help me put it away, which he did (what has happened to that tidy child now?!), he picked up little bits and put them back in the container. Eventually I could get him to squash the play dough into the container so we could fit the lid on. I gradually increased the size of the play dough bits and he gradually got used to the texture. He will tolerate play dough now, and sometimes even chooses to play with it.

The OT used to bring around a container filled with rice with various things hidden in it. Michael eventually tolerated putting his hand into it to find the objects. The OT also showed me how to do Brush therapy

If he fell over, he was usually more upset about the dirt on his hands than the skinned knee!

and joint compressions and these seemed to help, although Michael only let me do this for a little while and then refused to be brushed any more.

I have a photo of Michael sitting wearing shorts in a nearly empty sand pit at the age of about 4 ½ - it was the first time he had ever gotten that close to sand!

Michael is now almost 7 years old. He still has trouble with thick, goopy textures. I don't think I have any finger paintings

done by him! He won't eat Weet-Bix for breakfast (they go mushy in the milk!). But mostly he can get by in everyday life without being troubled. I don't think he has outgrown the problem, just that as he is more able to control his environment it is easier for him to avoid those things that bother him.

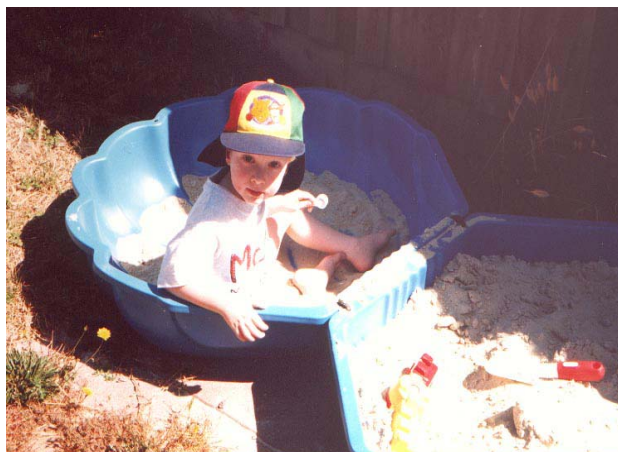
Sounds do still bother Michael, and this has been a problem at school, at times. He now has an arrangement whereby if he is bothered by the sounds in the classroom, he is able to go and work in the withdrawal room. He also usually helps out in the Library rather than going to performances that are sometimes held for the students.

Reading over this, none of it sounds so bad, but I can't begin to describe how upset Michael could get by a background noise that bothered him, or how difficult it was just to get him to play when he was so stressed by the grass, sand and dirt outside. His Kinder teachers worked really well with him to help him to just tolerate the environment he found himself in. If Michael hadn't had the help he needed at Kinder, I think he would have found school much more difficult.

My advice to anyone who thinks their child may have difficulties with SID is to find an OT who knows about SID and get their advice. The help we got certainly made a big difference.

Kirsten Burkitt
mum to

Michael 31 weeks now almost 7 years
and Rebekah, full term now 3 ½



Michael sitting in the sandpit for the first time!

AGM

Austprem Inc.

**Official Notice is given of the
Annual General Meeting
to be held on
Sunday 21st September 2003
at 8:30pm (Melbourne time)
in the Austprem Chat Room**

Nominations for the positions listed must be made on the Nomination Form (see the AGM notice in the Shared Files area of the the Forum, or contact kirsten@austprem.org.au) and will be accepted until 5:00pm, Sunday 14th September 2003

All nominees for positions, as well as those wishing to nominate someone or to vote in any election, must be registered members of Austprem Inc.

To register, please complete the form at <http://www.austprem.org.au/about/membershipform.html>

Registration is FREE

Positions

President

Vice President – Research Projects

Vice President – Special Projects

Treasurer

Secretary

Promotions Officer

Chat Host Coordinator

Newsletter Editor

State Representatives

(for further details, please see Position_Descriptions.doc in the Shared Files area of Austprem and Austprem – Pregnancy Support Group)

Survey

The Austprem Development Group is evaluating the service that we currently provide and is also considering what other services we might offer in the near future. We value your opinion and would like you to complete a short survey.

The survey asks questions about the service that Austprem currently provides and about your usage of the forum/message board and chats. We also ask you what you think we could do to improve what we currently do and your thoughts on some services we might offer in the future. We are especially interested in hearing from our members who have never or rarely used the forum/message board. The survey will take approximately 5 minutes to complete and your comments are a very important part of our evaluation process.

Please go to the survey at <http://www.austprem.org.au/survey/html>

The survey can be completed anonymously if you wish, however if you would like to be in the running to win a voucher from wishlist.com, you will need to include your name and email address so that we can contact you. Surveys must be submitted by 31st October 2003 to be eligible to win the voucher.

Thankyou for taking the time to help us help you.

Survey

**Submit by 31st October and include your name
and email address and be in the draw to WIN a
voucher from wishlist.com**

<http://www.austprem.org.au/survey.html>

AGM

**Sunday 21st September at 8:30pm in the
Austprem Chat Room**

**Nominations for positions close at
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**To nominate, be nominated or vote you must be
a registered member of Austprem.**

Register now at

<http://www.austprem.org.au/about/membershipform.html>

Registration is FREE!

Further Reading

Always check with your baby's doctor or other healthcare professional as to whether any practice or procedure you read or hear about is appropriate for you and your baby/child.

Websites:

<http://www.nthadelaideps.sa.edu.au/sensory/article.html>

http://www.healthatoz.com/healthatoz/Atoz/ency/sensory_integration_disorder.html

http://www.comeunity.com/disability/sensory_integration/

<http://www.geocities.com/~kasmom/sid.html>

<http://www.sinetwork.org/home/index.html>

<http://home.earthlink.net/~sensoryint/faq.html>

<http://www.out-of-sync-child.com>

Chats

Chats are a great way to get to know other members better. They are usually held on Thursdays (9pm EST) and Sunday nights from about 9pm (EST).

A reminder is posted to the Austprem Forum the day before a chat, so check there for the exact time. The chats are held in the Austprem Chat Room on the mc2 site, so only Austprem members are able to attend.

We are hoping to hold some special topic

"You can turn up in your pj's and you don't need a babysitter"

Austprem Membership

Austprem is an internet based support group, providing support to anyone that needs it.

We ask that you consider becoming a Registered Member. Registered Members are eligible to join the Austprem Development Group to help to improve and promote Austprem.

Registered members are also able to vote at the Annual General Meeting, so having a say in how Austprem Inc is run.

Books

Too loud, too bright, too fast, too tight : what to do if you are sensory defensive in an overstimulating world

Sharon Heller

The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction

Carol Stock Kranowitz, M.A

Register online at

<http://www.austprem.org.au/about/membershipform.html>
it's FREE!

chats, so if you have a topic you would like to discuss, or know of anybody who could lead such a discussion, please let us know, either via the Forum or direct to leanne@austprem.org.au

Chats are very informal—you can turn up in your pj's (who's going to know?) and you don't need a babysitter. But you can still receive great support and understanding from other parents, or just have a social chat—a bonus if you have been isolated at home all day.

Registration is FREE and open to all Austprem and Austprem - Pregnancy Support Group members. Donations you choose to make are tax deductible and will help us to achieve our goals.

Any information provided to Austprem is held in confidence and will not be used for any other purpose or given out to any third party without your permission.

Book Review: The Out of Sync Child

"If your child has been labeled with words like difficult, picky, oversensitive, clumsy, or inattentive . . . there may be a new explanation - and new hope."

- Front cover quote.

The subtle nature of Sensory Integration Dysfunction makes it an ambiguous issue, more so for "normal" kids than for the premies who tend to be (or should be) under the microscope developmentally. Through the book we learned the importance of a child's developing senses and how, with the amount of sensory activity a child experiences, the infant brain can easily misinterpret sensory signals.

The introduction states "We need to remember that behaviors are a message, a symptom, not a diagnosis" and the book does indeed give us a clear insight into the signposts of sensory development. It empowered us to identify the areas where Finn's sensory development was outside of "normal" and then gave us strategies to get Finn and us through his "difficulties" with a great degree of success. The same difficulties, mind you, that various "experts" poo-poo'd or told us that Finn would grow out of.

"The Out-of-Sync Child" is written for the layman to understand and spells out in words of one syllable what Sensory Integration Dysfunction is as much as what it isn't.

I would as a matter of course recommend this book for all parents, at least to draw our attention to and make us sensitive to the very important process of a child's developing senses. Those of us with "normal" children will at least find the information and activities detailed a positive influence. For those of us outside the normal and struggling with an "out of sync child", this book is an invaluable resource.

Dave McCarthy

Dad to Finn, 25 weeks now 2 years

Birthdays

August

- 2nd Robert (3)
- 6th Jayden (5)
- 13th Elizabeth (11)
- 16th Nicholas (3)
- 25th Benjamin (2)
- 26th William (10)
- 26th Daniel (6)
- 29th Saffron (3)

September

- 3rd Matthew (2)
- 23rd Casey (4)
- 23rd Connor (1)
- 25th Michael (7)
- 25th Cameron (6)
- 30th Renee (4)

If you would like your children (full term and prem) added to the Birthdays page at www.austprem.org.au/superheroes/birthdays.html or to be listed in the Newsletter, please tick the appropriate boxes when you register as a member of Austprem <http://www.austprem.org.au/about/membershipform.html> or email kirsten@austprem.org.au

October

- 6th Vincent (9)
- 6th Liam (3)
- 28th Emily (6)

November

- 9th Jack (4) 
- 11th Cassie 
- 12th Lewis (10)
- 12th Kyle (10)
- 15th Jordan (9)
- 17th Cody (1)
- 21st Thomas (2)
- 21st Jessica 
- 26th Zac (2)

Austprem Inc. - Membership Registration Form

You will need to send this form to the address below, or register online at <http://www.austprem.org.au/about/membershipform.html>

Name _____

Address _____ Post Code _____

Phone _____ Email Address _____

I am applying to join Austprem Inc. and agree to abide by the Rules and Guidelines of the Association
Membership cost per year Free

I would like to make a donation to Austprem of Donations \$2 and over are tax deductible.
Cheques should be made out to Austprem Inc.
\$20 \$50 \$100 \$other \$ _____

Signed _____ Date _____

Please forward this form to:
Austprem Membership Secretary, P.O. Box 2157, Sunbury Vic 3429

Baby's details (New members please complete)

Baby's name _____ Male/Female

Date of birth _____

Gestation _____ Weight _____

Hospital _____

Parents' names _____



ABN 67 731 996 316

Austprem Inc.

Supporting families and caregivers of premature babies and children

Visit our website
www.austprem.org.au

Contact Us:
leanne@austprem.org.au
kirsten@austprem.org.au

Newsletter Suggestions and Comments?
newsletter@austprem.org.au

Coming Up in the Next Issue...

Post Traumatic Stress Disorder

Post Natal Depression

Both of these issues are very sensitive and we will welcome your input and experiences if you want to share with us.

newsletter@austprem.org.au



PremiePress is a publication for those who are interested in the development of premature infants and prematurely born children.

The first edition may be viewed online at <http://www.premiepress.com/>

For further information and subscription details please contact:

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Austprem is proudly sponsored by **earlybirds** :
beautifully crafted clothing for premature and small babies
<http://www.earlybirds.com.au>



Please support those that support us.

Disclaimer

Please note that Austprem Inc. does not recommend that any interventions are made to any baby or child without the knowledge and assent of the child's doctor or other health care provider.

Austprem Inc. cannot be held liable for the actions of any person based on information that Austprem Inc. has provided.

Please check with your doctor or health care provider as to what interventions are appropriate for YOUR baby.

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