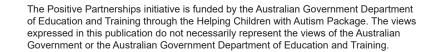


# GET TOGETHER

Support Booklet





#### **Cover's Artwork**

The artwork was designed and painted by artist Maria Watson-Trudgett, with a perspective of working together to build strong positive partnerships. Maria is a WIRADJURI person of NSW and Positive Partnerships Team Leader for Aboriginal and Torres Strait Family & Community Programs.

#### **A Working Together Journey**

The story tells of Positive Partnership in the centre with all its team members. Flowing lines moving out is our journey, dots/and circles represent us branching out in to states, territories and communities, supporting all people and families with a person on the spectrum, or with a diverse learning need. Outside of the centre area, also represents the people who become facilitators of Positive Partnerships material, as they too become part of this journey.

#### **Acknowledgement**

Positive Partnerships acknowledges the Traditional Custodians of these lands; we pay respect to their Elders past and present.

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#### **Disclaimer**

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Every attempt has been made to ensure the accuracy of the information presented at the time of publication. If you are aware of any information that requires updating please contact Positive Partnerships on 1300 881 971 or positivepartnerships@autismspectrum.org.au

## Acknowledgements

The Positive Partnerships *Supporting school aged students on the autism spectrum* initiative is funded by the Australian Government Department of Education and Training through the Helping Children with Autism Package.

An extensive writing team was involved in the development of the original Positive Partnerships materials in 2008, and subsequent annual content reviews from 2009 – 2015 for both the Professional Learning and Parent/Carer components. The outstanding contributions from everyone involved, including subject experts, educators, allied health professionals, people on the autism spectrum, parents and community representatives from each state and territory of Australia are sincerely acknowledged.

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Aboriginal and Torres Strait Islander Peoples should be aware that this publication may contain images, works or names of people who have since passed away.





## **Get Together for community**

The Get together workshop and content was originally created and developed in collaboration with the Aboriginal community in Moree, NSW in 2013 after months of community planning.

Positive Partnerships' Aboriginal and Torres Strait Islander team are committed to the ongoing review of the workshop and resources, informed by Get Together participants and other community members across Australia. The Positive Partnerships Aboriginal and Torres Strait Islander reference group also guide and shape the development of new resources in response to community needs.

## **Get Together - Workshop**

#### Why are we getting together?

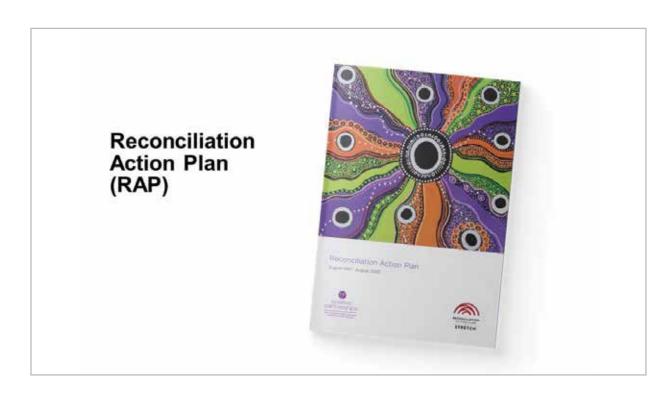
The Positive Partnerships team is deeply committed to working positively and in culturally sensitive and meaningful ways with Aboriginal and Torres Strait Islander peoples to talk about children and young people.

We know that all parents are on a journey of learning when it comes to understanding and supporting their young people. The Get Together is an opportunity to focus on you and your child/ren. Together, we can yarn and share our experiences and stories, explore the different ways children learn and behave and explore the most effective ways we can work together with family and extended mob, schools, and community to make sure positive partnerships are well established.

During the workshop we will be talking about:

- Children that learn and behave differently etc.
- Learning about the senses
- Behaviour
- A resource to help you work with school and community- My Child's Story Book
- Working together
- Voices from Aboriginal and Torres Strait Islander families





## **Reconciliation Action Plan (RAP)**

#### Key messages:

### **Positive Partnerships Reconciliation Vision statement**

Positive Partnerships believes in possibilities and what can be achieved by working together. Our vision for reconciliation is a nation of strong communities built upon working alongside Aboriginal and Torres Strait Islander peoples, and based upon pride in Aboriginal and Torres Strait Islander cultures. We envisage an Australia where Aboriginal and Torres Strait Islander peoples are empowered to connect and work in collaboration with each other, and all Australians, to create opportunities that contribute positively to the future of First Australians.

We will continue to work alongside First Peoples of Australia to develop and strengthen approaches that:

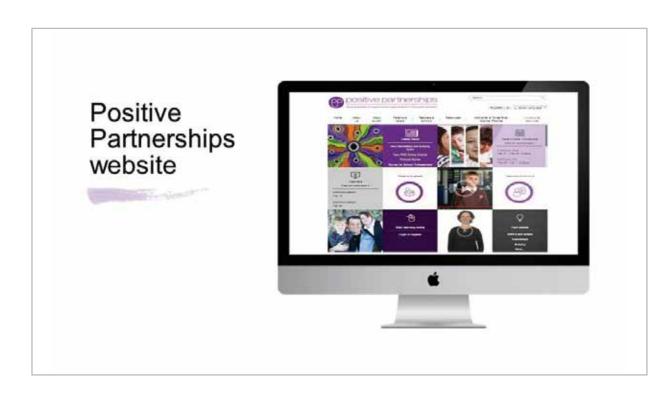
- improve educational outcomes of school-aged children on the autism spectrum
- build relationships with people from diverse communities
- respect the relationship between land, people and culture
- create sustainable opportunities that support the future of Aboriginal and Torres Strait Islander Peoples
- inform and educate the community to reconcile the past and work towards a common future.

#### About the artist:

Maria Watson-Trudgett a Wiradjuri person.

Artwork: Collaboration.

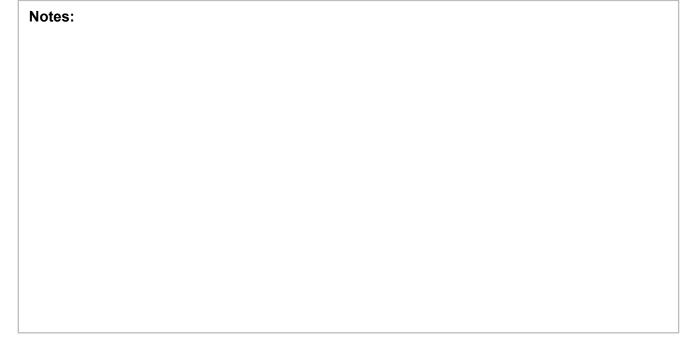


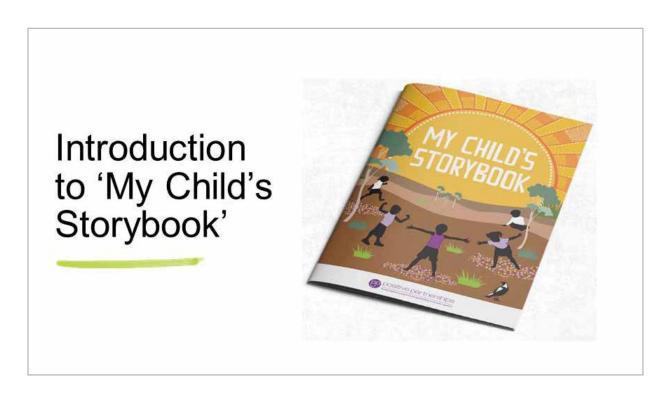


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### Key resources available:

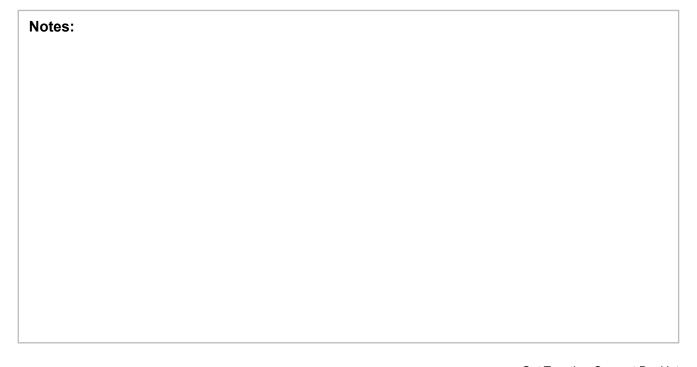
- Information sheets
- My Child's Story Book
- Storyboard
- Animations and family stories
- Autism, Our Kids, Our Stories-Voices of Aboriginal Parents across Australia
- Story books for children, families and schools.

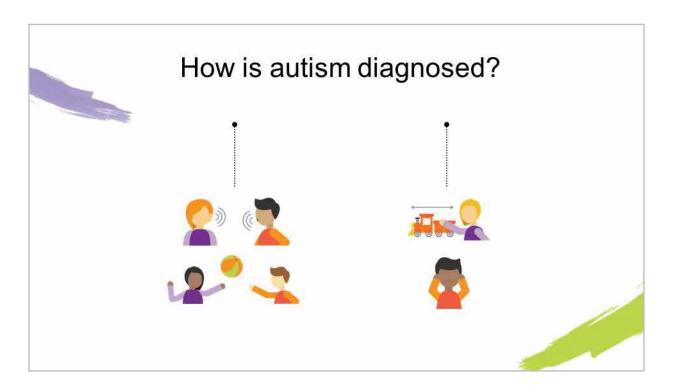




## Introduction to 'My Child's Storybook'

- My Child's Storybook is a meaningful resource to help your child to be understood.
- This book can help tell your child's story: what they like and enjoy, how they learn and what helps them cope in different environments.
- Positive Partnerships acknowledge that connection to culture is the foundation of a child's positive learning outcomes.
- This book can be used to highlight children's strengths, interests and abilities.
- It can be shared with school, family, community and professionals working with your child.





## How is autism diagnosed?

### Key messages:

- Autism is a complex condition that affects individuals in a variety of ways.
- While facilitators are not experts on autism, we offer information based on current research today.

#### To learn more:

Refer to the 'What is Autism?' fact sheet for further information.

Notes:	

## Fact Sheet

## What is Autism?



Working together to support school-aged students on the autism spectrum

### What is Autism?

- Autism is also known as Autism Spectrum Disorder.
- Autism is a developmental disorder that occurs in both boys and girls across all cultures and communities.
- Autism affects how a person learns and how they interact with others and their surroundings.
- All people on the autism spectrum are unique.

What are some of the characteristics of autism?

People on the autism spectrum often have problems with communication skills, social situations, behaviour, coping with their environment and learning.

- **Communicating:** People on the autism spectrum may have problems understanding others, talking about their own feelings, following instructions, or maintaining a conversation.
- **Socialising:** People on the autism spectrum may like to play alone or may have problems making and keeping friends. They may not know how to join in a game or activity with others so they find social situations difficult.
- **Behaving:** People on the autism spectrum may have problems behaving appropriately in certain situations and environments. They may dislike change, have a strong interest in one topic or repeat actions or movements over and over again.
- **Coping with the environment:** People on the autism spectrum may have problems coping with noise, touch, certain smells, certain tastes, movement or people and objects around them.
- **Learning:** People on the autism spectrum may find learning difficult at times due to problems with attention and concentration, planning and organisation, understanding what is expected and staying motivated.

People on the autism spectrum have strengths and skills too so with regular, consistent support, progress can be made.

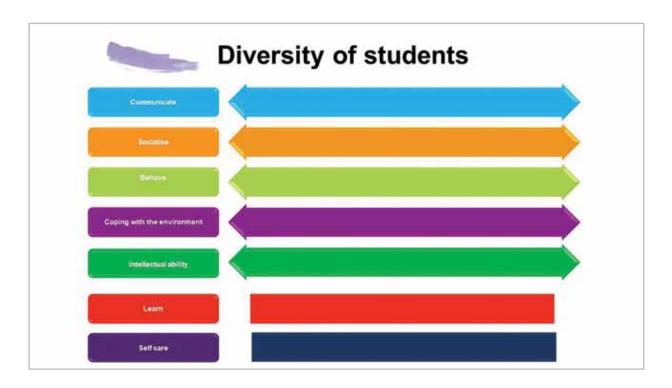
What can you do if you are worried about your child?

Children do develop at different times and rates. If you are concerned about your child's development see your doctor or child health nurse. It is better to have any concern checked than to 'wait and see'.

Visit the Positive Partnerships website for more information www.positivepartnerships.com.au

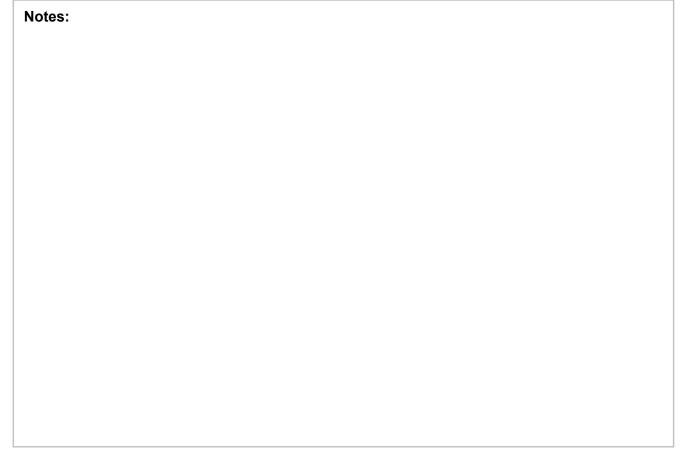






## The diversity of students

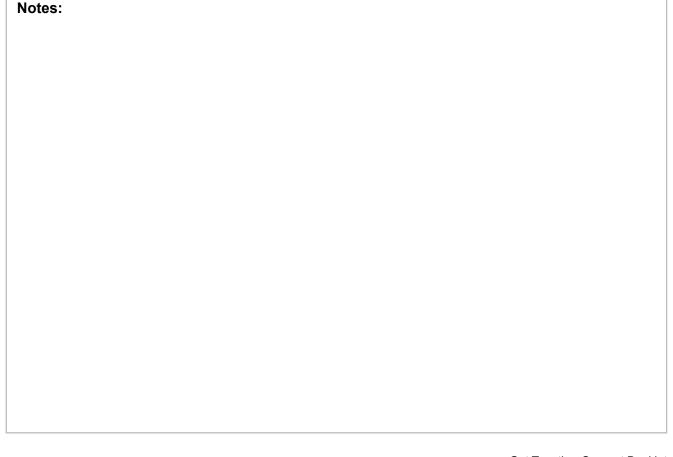
- There are 5 core characteristics we explore when we talk about autism, as well as self care and intellectual ability.
- Autism is unique and no two individuals are the same.





## Capture your child's strengths

- Who is your child? Highlight their strengths, knowledges and interests in the front of the book e.g. their favourite things to do.
- Take some time to record important information.





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## How your children communicate

Let's yarn about communicating

## Does your child:

- avoid talking to people?
- find it hard to follow or understand instructions?
- · talk too much?
- get frustrated when trying to talk about things?
- play with objects and things instead of people?

## If you answered yes, this may mean your child:

- does not know how to communicate
- · does not understand what is being said
- does not know when to talk or when to stop
- · does not know how to play with people
- feels frustrated that others do not listen
   to him or her

## If your child behaves like this, you could try:

- getting their attention first by using their name
- · telling them one thing at a time
- getting down to their level to yarn with them
- giving a positive response when your child responds correctly
- using visuals pictures or words on cards that help to explain these ideas

## **Important:**

If you are concerned about your child's development, see your doctor or go to a child health centre.

DON'T 'wait and see - ACT NOW

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## How your children socialise

Let's yarn about socialising

## **Does your child**

- play alone or prefer younger or older children?
- have trouble joining in games?
- find it hard to adjust to new or different people?
- have little awareness of other people's feelings or interests?
- have trouble talking with others?

## does not understand how to make friends

this may mean your child:

If you answered yes,

- is vulnerable to bullying
- feels frustrated by the constant changing of environments
- does not understand how to show other people how they are feeling
- does not know how to respond to others

## If your child behaves like this, you could try:

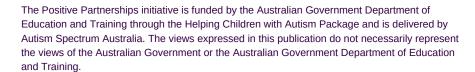
- explaining emotions using pictures or drawings of faces, colours or a social story
- using visuals pictures or words on cards that help to explain these ideas
- · watching videos of children playing
- joining a small group based on their interest
- giving your child information about changing situations

## **Important:**

If you are concerned about your child's development, see your doctor or go to a child health centre.

DON'T 'wait and see - ACT NOW

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## How your children learn

Let's yarn about learning

## Does your child:

- not always respond to their name?
- not always understand what you have said?
- sometimes forget what you have asked them to do?
- · focus on the small details?
- find school work hard?

## If your child behaves like this, you could try:

- visuals pictures or words on cards that help to explain these ideas
- getting their attention before you talk to them
- focusing on their strengths or interest areas
- teaching them one step at a time
- giving positive feedback when they do the right thing

## If you answered yes, this may mean your child:

- isn't sure what they need to do
- is mucking up at school or doesn't want to go
- has difficulty maintaining attention
- · does not understand the bigger picture
- need lots of help to learn new things

## **Important:**

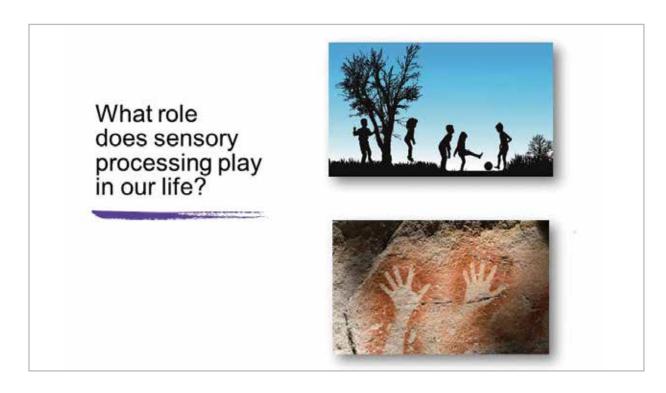
If you are concerned about your child's development, see your doctor or go to a child health centre.

DON'T 'wait and see - ACT NOW

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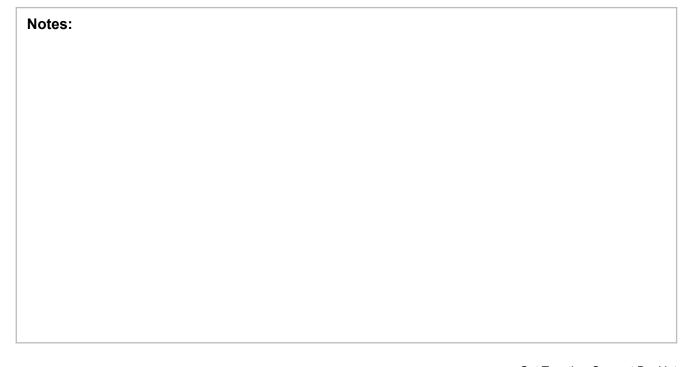
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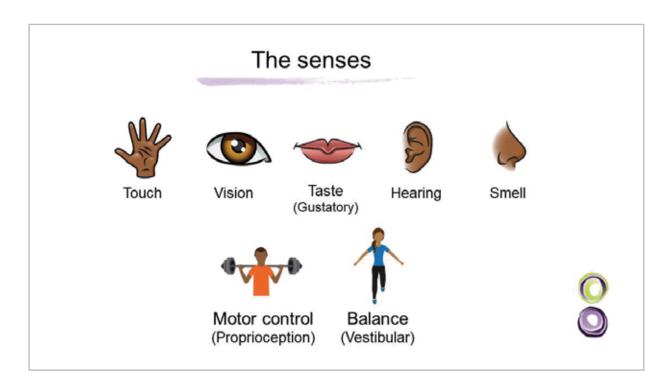




## What role does sensory processing play in our life?

- The sensory system impacts on everything we do.
- Sensory processing is the way the brain receives, processes and understands the information received from all the senses.
- Some children express their needs in ways that are challenging for parents/carers, yet the child is likely communicating a sensory issue.
- If we view challenging behaviours as communication, we can more easily figure out the problems.
- All people have unique sensory needs and preferences.

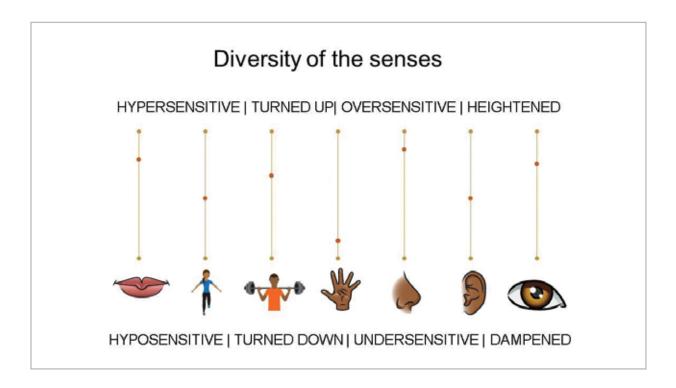




#### The senses

#### Additional notes:

- **Touch**: Also called the tactile system, this information comes from skin, and the inside of the mouth. Pain and temperature are also carried by this system and registration of these is important in protecting us from harm.
- **Hearing**: Also called the auditory system, this sense involves the ear and allows us to understand speech and environmental sounds. It helps us determine the pitch and volume of a sound and to locate the source of the sound.
- **Vision**: This sense enables us to make sense of what is seen. The eye is stimulated by light and provides information about objects, people, distance and helps us determine our position in space.
- **Taste (gustatory)**: Also referred to as the gustatory sense, this information is received via the tongue. It provides information about different types of taste (including sweet, sour, bitter, spicy and salty).
- **Smell**: Also called the olfactory sense, smell is the information received via the nose. It is closely related to taste and helps alert us to smells that could be dangerous.
- **Motor Control (proprioception)**: Provides us with information about where our body is, how it is connected and what it is doing. This information comes from all the muscles and the joints, giving us information about the position of our body, how we are moving and where we are moving in the space around us.
- **Balance (vestibular)**: This sensory system supplies us with information about balance and about how fast or slow our body is moving or responding to movement.



## **Diversity of the senses**

- Children on the spectrum are likely to have a unique mix of turned up and turned down senses.
- Hypersensitive is when a child is oversensitive to sensory input (i.e. getting too much information through one or more senses).
- Hyposensitive is when a person is undersensitive to sensory input (i.e. not getting enough information through one or more senses).

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#### Sense Impact of Oversensitivity Impact of Undersensitivity Heightened/Turned Up/ Dampened/Turned Down/ **Hypersensitivity Hyposensitivity** Moves stiffly Motor control Seeks deep pressure (Proprioception) Appears clumsy Loves 'roughhousing' Bumps into things Likes to crash, stomp, bear hug, etc. Complains of aches and pains Tends to move around a lot Unusual body positioning. May walk on toes May chew/suck things May fidget a lot May prefer tight clothing Sleeping issues Toileting problems (i.e. lack of awareness of need to go) May be 'rough' with others and objects Over-filling mouth while eating Drooling excessively. Balance (Vestibular) · Appears fearful of movement Thrill seeker Fearful of heights Difficulty sitting still Afraid of falling Constantly moving Dislikes being tipped upside down Never gets dizzy Dislikes playground equipment and May love to swing and spin showground rides Difficulties with spatial and motor planning particularly when movements are slow and Difficulty walking on uneven services controlled. Feels seasick/motion sick from movement. Avoids certain textures and surfaces • Tries to touch everything Touch Dislikes being touched Seems to be constantly touching Dislikes having dirty hands and feet Unaware of pain and temperature Overreacts to temperature and pain May smear faeces Discomfort with clothing/tags/shoes May mouth objects Resists cuddles May touch genitals Dislikes messy play May seek rough play Dislikes some hygiene routines and May bite his/her own skin haircuts Doesn't realise hands/face are dirty May avoid certain food textures/ Fails to notice nasal discharge and saliva temperature. or food around mouth and nose. May become distressed by loud noises May appear to ignore the voices of others Hearing Super-hearing – unable to filter out sounds May make a lot of noise Covers ears to loud sounds May love loud places and loud music Avoids noisy places Talks louder than other people May avoid or be fearful of toilets, hand-May appear not to know where the sound dryers, vacuum cleaners, etc. is coming from. Distracted by noises Complains about noises that others don't notice/aren't bothered by May make own noises like hum or croon to block out external noises.

Sense Impact of Oversensitivity Heightened/Turned Up/ Hypersensitivity		Impact of Undersensitivity Dampened/Turned Down/ Hyposensitivity	
Smell	<ul> <li>May comment on the smell of things</li> <li>Says other people smell</li> <li>Breathes through mouth instead of nose</li> <li>May avoid certain environments (e.g. toilets, fish and chip shops)</li> <li>Nauseated by cooking, bathroom smells or perfumes</li> <li>Chooses food based on smell</li> <li>Notices smells not noticed by others.</li> </ul>	<ul> <li>May smell everything</li> <li>Doesn't mind smell of their own bowel movements/dirty pants</li> <li>Doesn't notice noxious odours or other smells</li> <li>Not aware of own body odour/breath</li> <li>Not alert to smell of smoke.</li> </ul>	
Gustatory	<ul> <li>Gags or vomits easily</li> <li>Picky eater or an extremely limited diet</li> <li>Difficulties with sucking, chewing and swallowing</li> <li>Dislikes toothpaste and may be overly fearful of dentist</li> <li>May cover food in a preferred/familiar food, (e.g. sauce).</li> </ul>	<ul> <li>May eat everything including non-food objects</li> <li>May prefer strong tasting foods like chilli, garlic, spices, lemon, etc.</li> <li>May chew on clothing, toys, pens, etc.</li> <li>May mix unusual foods together, (e.g. ice-cream with tomato sauce)</li> <li>May regurgitate in order to get more information about the food.</li> </ul>	
Vision	<ul> <li>May be sensitive to light</li> <li>May be unable to block out unnecessary visual information</li> <li>Needs to wear sunglasses or a hat even indoors</li> <li>Likes rooms/spaces to be visually organised</li> <li>Avoids eye contact</li> <li>Turns away from a speaker/difficulty looking and listening at the same time</li> <li>May become over-aroused in busy environments</li> <li>May flap to screen out excessive vision</li> <li>Trouble locating things in a busy environment</li> <li>May look down to block out visual input.</li> </ul>	<ul> <li>May stare/needs a lot of time to look and take in information</li> <li>May look at objects for a long time</li> <li>May lose their place while they are reading</li> <li>Difficulty copying from the blackboard</li> <li>Difficulty with fast-moving stimuli</li> <li>May bump into people and things</li> <li>Intense interest in light, shiny or spinning objects</li> <li>May flap, squint or spin to get extra reliable visual input</li> <li>May touch objects to get extra information to compensate for difficulties processing visually.</li> </ul>	





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## Helping your children cope with the environment

Let's yarn about coping with the environment

## **Does your child**

- cover their ears to block out loud sounds?
- block their nose to avoid strong smells?
- need to move around constantly
- touch things, fidget and find it hard to sit still?
- refuse to eat certain foods?

## If you answered yes, this may mean your child:

- is finding it difficult to cope with certain sounds
- is finding it difficult to cope with strong smells
- is distressed at times by the environment
- · might only eat certain food
- can't sit still for long

## If your child behaves like this, you could try:

- using ear plugs or headphones when loud sounds are expected
- preparing your child in advance
- offering new foods in a way that interests your child
- using movement breaks like skipping, rolling or bouncing several times a day
- changing the environment around them at home to reduce stress

## **Important:**

If you are concerned about your child's development, see your doctor or go to a child health centre.

DON'T 'wait and see'
- ACT NOW

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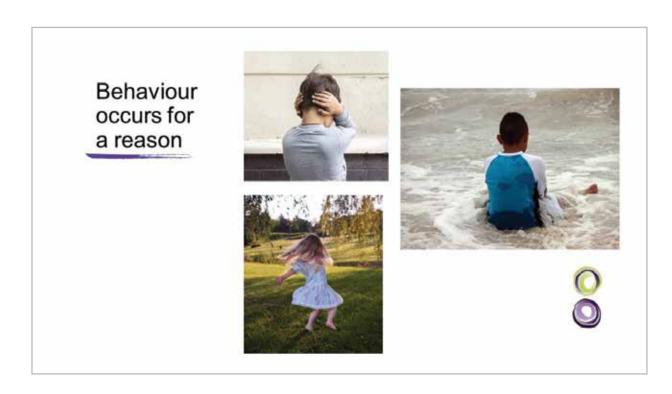




### Let's talk behaviour

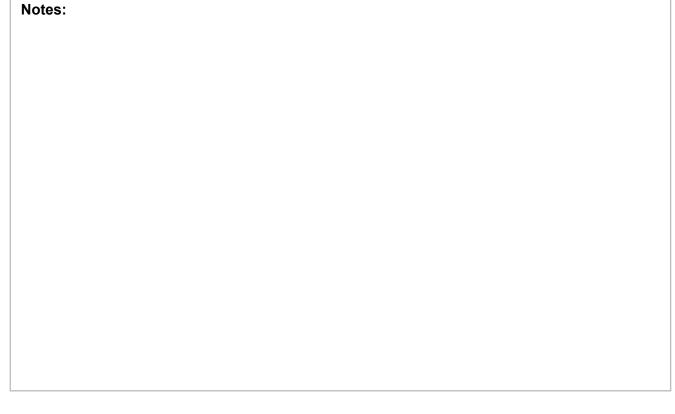
- Everything we say and do is behaviour.
- All behaviour serves a purpose.
- Behaviour can serve more than one purpose.
- Target one behaviour at a time.
- Identify the observable behaviour you want to change and identify when and where you want to stop it.

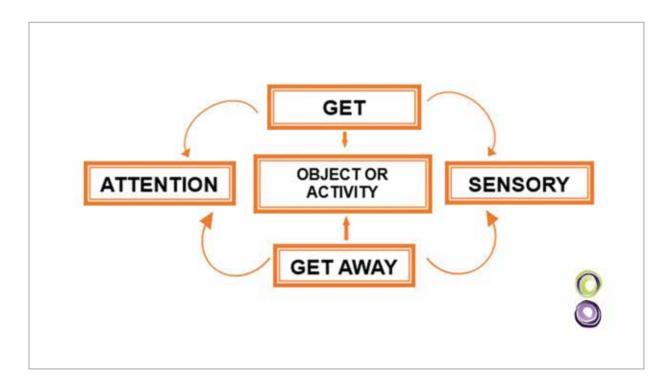
Notes:		



### Behaviour occurs for a reason

- Challenging behaviour occurs as a result of something called a 'trigger'.
- All behaviour serves a purpose.
- We must understand the purpose behind the behaviour before we can make any changes.
- Remember that the challenging behaviour you see is your child communicating with you.

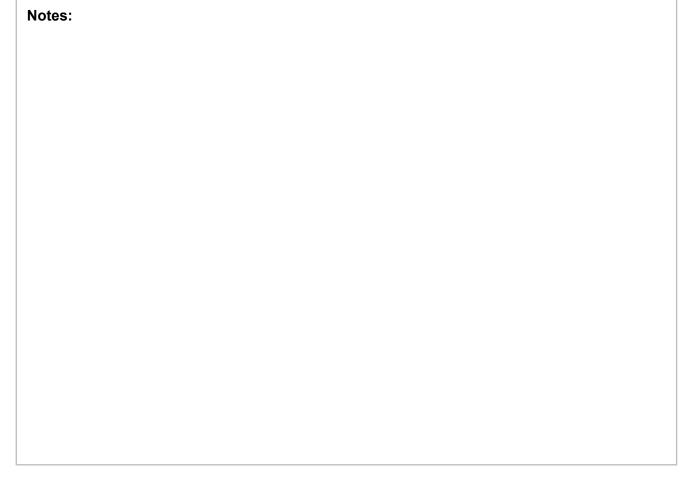


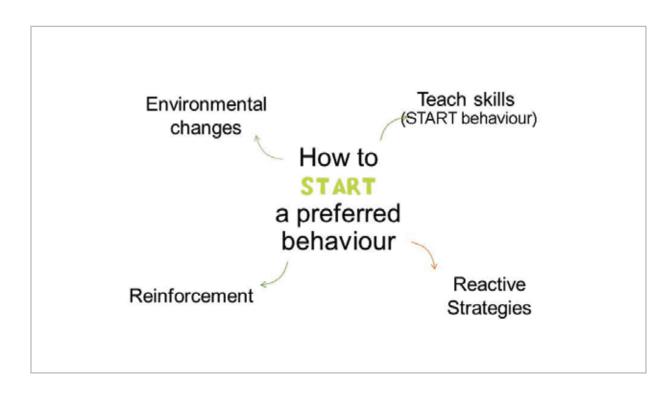


### **Function of behaviour**

### Key message:

 Before we can support a young person to learn new behaviours, we have to understand the function of their behaviour.





## How to start a preferred behaviour

- Inappropriate behaviours (undesirable, dangerous) can be replaced by more appropriate new behaviours – called start behaviours.
- Start behaviours must meet the same need and serve the same purpose if they are to be successful.
- · Replacement behaviours must be taught.
- Replacement behaviours will only occur when the environment is adjusted, the skills are taught and the behaviour is reinforced.

Notes:	



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## How your children behave

Let's yarn about behaving

## Does your child:

- like to do the same thing over and over?
- have trouble with change?
- need to follow a routine?
- · rock, flap hands or walk up on tip toes?
- play with toys in different ways to other children e.g. spinning wheels or lining up toys?

## If you answered yes, this may mean your child:

- misses out on learning new things
- feels upset or worried when things change
- · finds it hard to join in
- hurts themselves or others accidentally
- damages their things or other people's
   things accidentally

## If your child behaves like this, you could try:

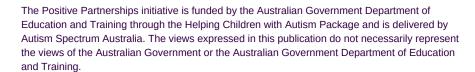
- visuals: pictures or words that help to explain ideas
- teaching them something new with their favourite thing
- talking to them about changes before they happen
- offering your child some choices
- teaching them a routine with time frames

## **Important:**

If you are concerned about your child's development, see your doctor or go to a child health centre.

DON'T 'wait and see - ACT NOW

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## **Working together**

- Everything we have learnt, heard and experienced during the Get Together can help us to work more closely with people that support us and our children.
- · Working together can help keep us stronger.
- Working with others can strengthen our networks of support.
- With our strengths, skills and knowledge about our children and our cultures, we can make connections to help get the best support across all environments.

Notes:	







These support tips have been gathered from the voices of Aboriginal and Torres Strait Islander parents, carers and staff at previous workshops. They hope their tips encourage and support you.

- Get a manicure or pedicure
- Host a clothing or Tupperware party
- Have a bath without interruptions
   Mum - Shepparton, VIC
- Talking to my sister
- Sitting quietly

  Grand-mum 
  Yuendumu, NT
- Go to the bush
- Visiting a friend
- Volunteering
- Go to the river

  Mum 
  Broken Hill, NSW

- Read books
- Debriefing
- Talking with a friend Teacher
  - Arnhem Land, NT

- Going to bingo

  Education Support Cherbourg, QLD
- Go to car shows
- Do art
- Bush walking
- Going to a men's shed Dad - Coffs Harbour, NSW

- Go to the beach
- Listen to music
- Meditate
   Mum Coffs Harbour,
   NSW

- Advocate for my child and our rights
- Supporting my wife Dad - Armadale, WA

- Visiting a family
- Going to sport
   Mum Port Lincoln,
   SA

- Visiting an auntie
- Watching a movie
- Getting a massage *Mum - Alice Springs*, *NT*

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### MURRI

## A Story by Jaqueline French

Yaama.

I would like to acknowledge the Central Arrente people as the traditional owners and custodians for Mparntwe, Alice Springs. My love and respect to our ancestors and to our elders, both past and present.

My name is Jacqueline French and I am a Murri woman from the Gomilaroi and Anaiwan tribes of north west NSW. My dreaming is the Yurundiali (Goanna).

I am the mother of thirteen year old Murri-Jak.

Murri was diagnosed with Autism Spectrum Disorder at two and a half years.

Murri (meaning Aboriginal person in Gomilaroi) was born at twenty four weeks gestation and from the day he arrived in the world he has fought to survive and make sense of the world.

Murri was a thriving, happy and normal baby until around the 16-18 month stage. Overnight he lost the ability to say Mummum, Daddad and Bubba. When I noticed that Murri was more engrossed with playing with the fluff on the carpet than he was with me, I knew something was wrong but I put it down to him being born so prematurely.

Initially Murri was tested for hearing difficulties and I was told that he had 'selective deafness'!!! The reality was so much bigger.

Our local GP referred us to a neurologist in Newcastle who diagnosed Murri within 10 to 15 minutes of watching his behaviour with attempts to engage him in age appropriate activities. Instead of responding to the doctor's requests for interaction, Murri was more interested in pulling on the stethoscope and turning on the taps of the clinic washbasin.

When I was told of Murri's condition, I naively asked what could be done to 'fix it'. I was not prepared for the words 'life-long disability'. I felt as though I was about to pass out.

I didn't ring my family or my partner with the news of Murri's diagnosis as I hadn't really digested it myself. I couldn't absorb it because I didn't know what Autism was. I was very confused and felt very alone.

The day Murri was diagnosed with Autism is the day my life changed....drastically.

When I got home I had nowhere to go. I wanted to know about Autism, find out what treatments were available and I wanted to know what kind of life my son was going to have. I desperately sought out other mothers of children with Autism. I wanted to learn about my boy.

The only place I had was the local library where I can vividly remember hiding in the aisles and crying my eyes out as I read extracts from different books on Autism. Every word was a physical blow to my heart. It was very hard to deal with and I spent a long time grieving for my 'lost' boy. I remember attending my first information workshop which felt more like the funeral for my hopes and dreams as I cried the whole time.



The following years were extremely difficult. I wasn't coping very well and I felt totally abandoned by my friends and some family members. Murri's behaviour was becoming very erratic and this added to my feelings of isolation as I thought people wouldn't understand and also because I still didn't understand it myself.

When I first told my parents and siblings what Murri's diagnosis was they all asked 'what's that?' and 'can they fix him?'. None of us really understood what Autism was so it became a process of not just educating myself but ensuring that our families and the community on whole were also informed and aware of Murri's different needs and behaviours.

Between the ages of 3-5, children with Autism are especially difficult in terms of establishing daily patterns and learning of behavioural triggers, therefore, psychologically I was ready to crash. It was all just too much. It was following an incident when I took Murri to see the doctor because he hadn't slept for close to forty eight hours and I was exhausted, that local services were contacted in regards to respite.

Murri had already been attending an early intervention programme two mornings per week, but this was having very little effect for him. Although new to the Autism world, I knew that Murri needed a more intense behavioural management programme and that early intervention was not providing the consistent intensive therapy that Murri urgently needed.

Around the age of four and a half Murri started pre-school for two mornings a week, combined with two mornings spent in what was to become his future special ed. Class.

For Murri to attend pre-school, funding was sought to employ a one-on-one aide. During the initial stages I was consulted and advised of every detail but following the resignation of the aide, another was hired without my inclusion or consultation. Murri would come home from school very stressed and high wired. I couldn't understand why. After observing Murri with the aide, it was clear that he couldn't cope with the pitch of her voice. I pulled him out of pre-school because I didn't want to go through the whole process of waiting for another aide to be hired and because I couldn't handle watching him experience a 'meltdown'.

The following year Murri stared school full time in a high needs special education class. The first few years were okay but as Murri grew so did his behaviours and many times I was contacted because the teachers and aides couldn't cope with him. It got to the point where I would refuse to let them send him home and I'd tell them to learn to cope with him or go get another job.

The year he turned eleven I had many visits to the school with the principal and the school counsellor who seemed hell bent on Murri attending high school the following year. I was dead set against it as I felt that Murri was not ready for another schooling environment and that he had the right to stay in primary school until the end of his twelfth year. On numerous occasions I voiced my concerns but it seemed as though they were falling on deaf ears. I took matters into my own hands and contacted the regional manager for education who stepped in to advocate on my behalf. I was advised of Murri's rights and he was able to stay in primary for another year. This was an unnecessary fight for me however I was left with no alternative as I felt the school was trying to push him out.

During the years Murri spent in infants and primary I was continually in search of more effective treatments for him. I always believed that Murri was and still is capable of learning much more, and had his educational program been more specific and structured to his needs, I feel he would have made a lot more progress in terms of communication and coping skills.

When Murri was nine I learned of Woodbury – the only specialised school in NSW that practices ABA (Applied Behavioural Analysis). I was determined to find a way to get my boy in to this school, even though it meant re-locating to Sydney and miraculously scraping together \$1000.00 per week for the fees. I knew I'd never have that kind of money but one way or another I was sure we'd cope. I was convinced that if Murri were able to access this treatment it would help to bring him through.



I completed the necessary application and even travelled from Moree to Sydney for information sessions. The following April I received an email from the school notifying of a placement for a child with his age range and a request for a very detailed application package including a DVD of Murri within a school setting and at home. I was given two weeks to compile all the information in order for a selection panel to assess his 'suitability' for the school. Because it was during the school holidays that I received the notice I wasn't able to complete the DVD until school had started back. I made a request to submit the DVD by the end of the first week upon return to school. Before I even had a chance to get footage I was notified that Murri couldn't be offered the placement as the panel had already selected a child. It didn't surprise me as there were no other Aboriginal children enrolled in the school and it seemed as though it was only accessible to the elite.

I believe there is a big gap between the quality of treatments and accessible therapies for children with Autism. Unfortunately, a person's income and financial stability can determine whether or not a child with Autism will access the highly successful behavioural programmes.

In terms of therapy, Murri has been working well with cue cards, and together with his current school and the Northcott Society (which is new to Moree), we are currently working on building the range of visual cards that he can relate to. I am also trying to introduce gluten, lactose and casein free food products to his diet; however it is proving to be very difficult as he already has an established diet and the gluten free foods are very expensive.

At this stage, the visual cue cards are our main source for teaching communication skills and we have personalised them with language Murri recognises. He acknowledges certain Gomilaroi words so together with the photo we write those words alongside the English word. For example a cue card with a picture of his father will have the words Dad/Buubaa etc.

On a cultural level there are many differences to the range and scope of services that need to be provided for Aboriginal children with Autism and their carers. As an Aboriginal mother I have experienced countless barriers in terms of appropriate respite and recreation services, access to high level behavioural intervention and limited access to support outside my immediate family.

I do not access certain local services as I am continually frustrated by their inability to follow up with intervention plans specific to his current behavioural needs. I do not access the local SOS respite service because there are no aboriginal staff and the care workers did nothing but complain about his behaviours and that they couldn't handle him. I find our local DADHC worker to be very uncooperative and just puts more barriers in front of me instead of trying to help us through.

I am wary of working with non-Aboriginal people as they sometimes don't understand where I'm coming from and often my passionate demands for help have been misinterpreted as aggressive approaches but I've learned that if I don't speak up for my son, nobody will. Sometimes services cannot understand that it is culturally important for Aboriginal people to show respect for protocol by attending funerals and that during these times the need for respite can increase. My partner and I have had to miss many funerals or have had to alternate which one attends because we can't get extra respite. It's also important for services to understand that after years of doing the 'service beat' sometimes a parent simply just gets fed up with attending reviews and going through the motions of answering the usual round of repetitive questions. Home visits by services are needed on a regular basis as quite often I wasn't even up for getting out of bed let alone run around to different service provider meetings.

I have always felt it very important that Murri's care workers are Aboriginal for various reasons;

- 1. They persevere with him and do not complain if he's too confronting
- 2. He is known to different parts of the Aboriginal community and they take him to Aboriginal events
- 3. Provides consistency with his home life
- 4. He becomes a part of their family



For the past eight years Murri has had the same care worker for four hours respite per week. When alternate workers were tried he would have mini meltdowns so it was important that the service provider was advised of Murri's need for consistency and routine.

This particular carer lives on one of the missions in town and everybody there knows Murri. All the kids call out to him and acknowledge him at school and in social settings and this helps for my other two boys to see that their brother is loved and accepted by his community.

I have always made a point of including Murri in his community by taking him to places and events such as the pool, fetes, football games and NAIDOC activities. It is extremely important that communities acknowledge and appreciate their special needs people and I've always felt that Murri has the same rights as anybody else to feel like he belongs.

Before Murri came along, many Aboriginal people in my community weren't aware of what Autism actually is and how it affects people. Many speculated that 20-30 years ago certain people displayed signs of Autism but nobody knew what it was, therefore nobody spoke of it. They had their own special place within community and were loved and accepted just like Murri is. I believe that the whole community has a special responsibility to Murri especially his families. Many times a random neighbour has brought him home after he has escaped through a window to get to the park across the road or they've found him trying to get in to their car to be taken for a drive!!! I am fortunate that my neighbours and the Aboriginal community are aware of his disability and the majority look out for him, however it is a continual process of having to explain to, and educate people about Murri's disability and sometimes I get sick of it.

We have a huge extended family and most are aware of Murri. On many occasions teachers or care workers have been watched and sometimes pulled up by one of his mob for not handling him appropriately either at school or in a public setting. Sometimes this hasn't been very well received but Murri is very much loved and his elders genuinely worry for his well-being and for his cousins, who all regard him as brother. They are taught to always be respectful of him and to watch out for him. Both our families are very protective of Murri and he has his very own special place within both sides of his family.

For the men of my family, Murri's diagnosis was very hard and my father in particular went through an even harder time accepting that Murri had such a devastating disability. My father grieved for the man he should've been and the life he should've had. From the day he was born my father spent many hours with him whilst he was in the neo-natal unit and has formed a very unique relationship with him. Physically, Murri is getting too big and too strong for him now but dad loves to spend special time with him and will try to do what he can for him. Dad escorts Murri to and from school every day in a taxi and occasionally Murri will watch the football with him.

Murri is very fortunate to have many positive male influences in his life that love and protect him. He loves his grandfather and his uncles and has an unbreakable bond with his father.

My mother and my sisters provide endless support and even though they can't do for Murri because he's too strong for them, they will help me in any other way they can, whether it be looking after my other boys for a night or two, or they'll come and do some cooking or cleaning jobs that I can never get the time to do. Little things like this are a big help.

My family and friends have come to understand that as Murri grows I have had to make a lot of changes. We've had to cut back the amount of time my nieces can spend at the house, we can't have a big mob walking in and out of the house and we can't have too many sounds happening at once. Murri gets confused and cannot differentiate between sounds and this can cause a meltdown which can take hours to bring him out of. When he's ready for bed, the house has to be in total darkness and silence for him to sleep. Murri's bedroom is some distance from the bathroom, yet if a tap is dripping he will hear it and can't sleep. It makes it very hard for us to do a lot of things and time spent as a family away from home is very limited and selected.



This year Murri started high school and so far is doing very well. He participates in many social skills activities however the shopping ventures are hard for him as he has an aversion to the lights inside the supermarkets and cannot handle them for very long.

He is a strong and robust boy who enjoys a healthy and varied diet. He has sensitivities to any cold foods and doesn't eat fruit however he loves his meat, fish, eggs, and vegetable. He is a remarkably good looking boy and is extremely well built for his age. I receive many compliments for his looks!!!!

He is a very lovable and affectionate boy who loves to be cuddled and squeezed. He gives me kisses and likes to hold my hand. He is super active and loves to exert his energy with lots of physical activity. He likes jumping on a trampoline, water play, going for walks and climbing fixed equipment.

Murri is non-verbal and nappy dependent. He is currently medicated on a daily basis for his hyperactivity, a step I had to take not just for his safety and well-being but just as much for my own sanity too.

For the past year we have been receiving one full weekend per month of respite with extra nights allocated during the school holidays. The respite home is an hour away and his father and I choose to transport him ourselves because firstly it is more cost effective and secondly we feel more at ease knowing he's arrived safely.

I worry about my boy's future because I wonder who will take care of him when I'm not around. Ideally I would like the reassurance that there would be a group home for him to live in with full assistance. I would also rather that he live in a home with the special needs cousins that he is growing up with and a place where his family can volunteer their time to help.

I try not to think about the future too much as it can be very depressing and I can't afford to be down in the dumps all the time as Murri can pick up on my feelings and because he doesn't understand different feelings it creates a much more positive vibe in the house when I'm coping well.

There are so many layers to Autism that at times it can be very overwhelming and depressing. Many times I could've walked out the door and kept going and for a long time I went through the feelings of 'why me?' and 'why my boy' and occasionally I still experience those feelings. What helps me knows that I've been chosen by my ancestors to be Murri's mother. My mother and father always reminds me that for some reason my ancestors sent him to me as not every woman can handle such a heavy load. Every day is hard but every day I feel blessed to be his mother.

For a long time I grieved for him and dwelled on the things he couldn't do. Now I focus on what Murri can do and we work hard on continual improvement. Like every child, Murri likes to make his mum happy too and works hard to understand our routine. The best thing I ever did for myself was making the decision to go back to school. Of course I had to pull all my family support in but it is helping to empower me and my sons are feeling that strength. Murri drives me to be the best person I can be and he is the drive behind my relentless search for appropriate treatments and approaches for him.

Before my grandmother passed over to the Dreamtime she could see that something was wrong. She told me that 'God dealt me a dodgy hand......but if I play my cards right I can still win the game'. For me winning the game means never giving up and I'll never give up on my boy.

Yaalu.



