

**The Secretariat of National Aboriginal and Islander Child Care (SNAICC)**

**Early Days Project on Autism Spectrum Disorders  
August 2010**

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## **The Secretariat of National Aboriginal and Islander Child Care (SNAICC) / Early Days Project on Autism Spectrum Disorders**

### **BACKGROUND**

Early Days is a national program that provides free workshops for mothers, fathers and other family carers of children aged six years and under who have an Autism Spectrum Disorder (ASD). Early Days is part of the Australian Government's Helping Children with Autism package. The Australian Government has committed \$190 million for the four years up to June 2012 to deliver the package which includes:

- Autism Advisors
- Funding for early intervention services
- PlayConnect Playgroups
- Early Days family workshops
- An ASD website:  
[http://raisingchildren.net.au/children\\_with\\_autism/children\\_with\\_autism\\_landing.html](http://raisingchildren.net.au/children_with_autism/children_with_autism_landing.html)

The Early Days initiative was developed by a collaboration of organisations nationally recognised for their expertise in Autism and parenting, coordinated by the Parenting Research Centre.

The Parenting Research Centre approached SNAICC in mid 2009 to invite SNAICC to partner with them to help ensure Early Days is inclusive of Aboriginal and Torres Strait Islander families and meeting the needs of Aboriginal and Torres Strait Islander families parenting a child with an Autism Spectrum Disorder.

### **Autism Spectrum Disorders**

Autism Spectrum Disorder (ASD) is an umbrella term that refers to a range of conditions that share some common symptoms, including Autistic Disorder and Asperger's Syndrome. The causes of ASDs are unclear, but symptoms include difficulties with communicating, interacting with others and with behaviour. Autism Spectrum Disorder (ASD) is a brain-based condition – where the brain hasn't developed in a typical way. Although no two children with an ASD are the same, they all face challenges in interacting and communicating with others and with their behaviour.

The 2007 estimated prevalence of autism spectrum disorders across Australia of 62.5 per 10,000 for 6-12 year old children meaning **one child with an ASD for every 160 children** in this age group.

Children with ASDs may be diagnosed in their preschool years (usually when they are about two or three years old) or after they have started school. Children with Asperger's Syndrome are often not identified until the child is in the social setting of their school.

Diagnosis of ASDs has increased globally over the last two decades. The reasons for the increase are still largely unexplained, but they are likely to include changes in diagnostic methods and improved pathways to diagnosis.

At the state and territory level, as well as the national level, information about Aboriginal or Torres Strait Islander identification is not consistently available<sup>1</sup>, therefore it is not possible to make an estimate about the number of Aboriginal and Torres Strait Islander children with ASDs other than assuming the figure is close to the national average.

### **(SNAICC) / Early Days Project on Autism Spectrum Disorders**

#### *Project Objectives*

Three objectives were identified for the SNAICC / Early Days Project on Autism Spectrum Disorders

- 1.To ensure Early Days workshops are inclusive and welcoming of Aboriginal and Torres Strait Islander families and communities.
- 2.To help services and organisations working with Aboriginal and Torres Strait Islander (ATSI) families to adapt and deliver Early Days workshops directly to their families.
- 3.To develop other strategies for ensuring Early Days is inclusive of Aboriginal and Torres Strait Islander families and aiming to meet the needs of Aboriginal and Torres Strait Islander families parenting a child with Autism.

SNAICC saw this project as furthering the achievement of several of its broad policy priorities expressed as *Eight Priorities for Aboriginal and Torres Strait Islander Children* November 2009 please see Attachment 1.

The two SNAICC policy priorities that are of particular relevance to the project's aims are as follows:

#### *Support Families to Care for Children*

Aboriginal and Torres Strait Islander families provide children with a wonderful childhood that is enriched by family connections and cultural identity. Services engaging with Aboriginal and Torres Strait Islander families should aim to build on existing family strengths to assist families to build healthy relationships to care for themselves and their children. Child care, healing services, parenting services, housing programs and employment program are examples of the types of support that families need to provide children with a happy childhood that will be the foundation for their future success in life.

#### *Thrive by Five with Culture Alive*

Meeting children's health, development and cultural needs through programs that value learning and respect for culture is the best way to ensure improvements in Aboriginal and Torres Strait Islander children's long term well being and educational achievements.

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<sup>1</sup> MacDermott S. The Prevalence of Autism in Australia Can it be established from existing data? Overview and Report Autism Advisory Board on Autism Spectrum Disorders February 2007 p 55

A confident ready-to-learn Aboriginal or Torres Strait Islander child starting school is one who is healthy, has strong family bonds, who knows and is proud of his or her Aboriginal or Torres Strait Islander culture and who has participated in a quality early learning program. A high quality early learning program is one that has supported the child to identify with and feel proud of his or her Aboriginal or Torres Strait Islander culture. This support must continue through their school years to ensure their continued confidence and success.

SNAICC was very mindful of these policy priorities when thinking about how to best further the objectives for the project.

### **Guiding Principles for the Project**

Two key principles drove SNAICC's approach to furthering the project's objectives.

1. Listening to the views of Aboriginal and Torres Strait Islander people.

SNAICC is an Aboriginal and Torres Strait Islander organisation and as such its primary authority is Aboriginal and Torres Strait Islander people and their lived experience. SNAICC determined from the outset that learning about the variety of Aboriginal and Torres Strait Islander experiences of and perspectives on raising children with autism must be a priority within the project.

2. Providing something back from the project to Aboriginal and Torres Strait Islander families and communities as the project progresses.

SNAICC, as an Aboriginal and Torres Strait Islander organisation aims where possible to 'give' something immediately valuable to people and communities rather than simply 'taking' research with assurances of improved service delivery at an unspecified future date. This principle is similar to the mantra of Fred Hollows' national Trachoma and Eye Health Program "no survey without service."

### **Description of Project Elements**

SNAICC considered the project's objectives, our policy priorities, and the guiding principles above and in consultation with the PRC developed the following five elements for the project.

1. Aboriginal and Torres Strait Islander Child Care Centre *Understanding Autism Workshops*
2. Interviews with families and service providers.
3. SNAICC Website Focus Site
4. SNAICC Conference Presentation
5. General feedback and comments to Parenting Research Centre on cultural appropriateness of Early Days program elements.

## **ABORIGINAL AND ISLANDER CHILD CARE CENTRE *UNDERSTANDING AUTISM* WORKSHOPS**

The primary purpose of the SNAICC /Early Days Project *Understanding Autism* Workshops was to provide information about Autism Spectrum Disorder to Aboriginal and Torres Strait Islander child care centre staff.

The workshops were designed for staff and other community members working with children with Autism. The workshops were designed to provide information about Autism to better support families, children and the staff working with them.

Details of the workshops held are as follows:

- 14 April in Alice Springs - Central Australian Aboriginal Congress, Ampe Kenhe Apmere MACS centre.
- 21 April in Cherbourg - Gundoo MACS centre and IPSU Queensland.
- 23 April at Wollongong - Noogaleek Children's Centre (Wollongong), Gujaga MACS (La Perouse), Oorunga Wandarrah MACS (Campbelltown), Gudjahgahmiamia Wreck Bay (ACT) and Noah's Ark Nowra.
- 29 and 30 April at Broome - Jalgurr Guwan MACS centre and Broome Primary School.
- 24 June in Adelaide - A workshop for 12 MACS and other South Australian Aboriginal Early Childhood services.
- 6 July in Shepparton Victoria – Lulla's Children and Family Centre.

The workshops were run over five hours and covered the following:

- Background on Early Days.
- Background on SNAICC.
- Understanding Autism.
- Supporting families.
- Working with children who have autism.
- Questions and discussion about Aboriginal and Torres Strait Islander perspectives on bringing up children with ASDs.

### **The Role of MACS and other Aboriginal and Torres Strait Islander child care services**

SNAICC chose to deliver the workshops at Aboriginal and Torres Strait Islander child care services because these services have a long history of being trusted, respected and valued by Aboriginal and Torres Strait Islander families working in close partnership with them to raise children. Aboriginal and Torres Strait Islander child care services such as MACS (Multi-functional Aboriginal Children's Services) play a different and often a much bigger role in the life of the child and the family than mainstream child care services.

Key needs met by MACS and other Aboriginal and Torres Strait Islander child care services include:

- Children's spiritual, cultural, health, physical and emotional development

- Identification and response to children's special needs or disabilities;
- Enabling families to work, study, and care for other children, care for other family members, self-care when sick, stressed or undergoing health or other therapeutic treatment.
- Providing parents with information about a variety of child rearing and child health issues.
- Contributing to building the health, cultural and spiritual strength, education levels, employment opportunities and economic strength of the community as a whole and

Aboriginal and Torres Strait Islander child care services are non-government, community based and Aboriginal and Torres Strait Islander community controlled. The services belong to the community, and are run by the community, and families therefore know they will be culturally appropriate and feel safe to use them without fearing they will be negatively judged or misunderstood.

The Aboriginal and Torres Strait Islander child care centres contacted by the project enthusiastically took up the offer of a workshop. It was apparent at the workshops that knowledge about ASDs was very low among child care workers and community members generally, although centre directors knew more. Many of the centres could relate the characteristics of children with ASDs described at the workshops to children they had had in the centre or whom were currently at the centre but undiagnosed. The child care workers were particularly interested in the parts of the workshop that suggested ways to work more effectively with children with ASDs. The centre directors and other staff were generally also interested in how to engage families and issues surrounding obtaining a diagnosis for a child.

### **Workshop Evaluation Data**

-A total of 88 participants over 6 workshops.

-62.5% of participants were Aboriginal or Torres Strait Islander.

-Mean satisfaction score of 4.4 out of 5.

94.4% of participants agreed or strongly agreed that the content of the Early Days Workshop was helpful

97.2% of participants agreed or strongly agreed that the Early Days Workshop was easy to understand.

92.5% of participants agreed or strongly agreed that the Early Days Workshop length, format and types of activities were appropriate.

91.5% of participants agreed or strongly agreed that the Early Days Workshop content was relevant to their work

93% of participants agreed or strongly agreed that the Early Days Workshop addressed the questions they wanted answered about autism.

85.7 % of participants agreed or strongly agreed that after participating in the Early Days Workshop they feel more equipped to work with families where a child may have autism.

->90% of participants agreed or strongly agreed that the Early Days workshop was helpful, relevant, appropriate and easy to understand.

## **INTERVIEWS WITH FAMILIES AND SERVICE PROVIDERS**

SNAICC conducted in depth interviews with five Aboriginal parents as part of this project. Three lived in the metropolitan areas and two in rural towns. Four were biological parents and one was an aunty who had looked after her child since he was a just a few months old.

The following points summarise the findings from the interviews. The points made in this section are supported by quotes from interviews when appropriate. Attachment 2 is a story written by one of the interviewees after her interview and presented at the SNAICC conference in July 2010 in Alice Springs.

## **FEEDBACK FROM INTERVIEWS WITH PARENTS/ FAMILY MEMBERS**

### **Awareness of ASDs in Aboriginal and Torres Strait Islander communities**

The common view of the parents interviewed was that knowledge about ASDs is very low within Aboriginal and Torres Strait Islander communities.

Some of the parents shared their lack of understanding about what causes autism and were concerned that drinking during pregnancy may be a cause.

*“She drank throughout her pregnancy and they don’t realise what they do to these little fellas.”*

*“I thought ‘what did I do or didn’t do to cause it’.”*

One parent described her role in educating her community about autism through her son.

*“The community hadn’t had autism right directly in their face until (child) and when I educated them some said ‘oh that’s what was wrong with so and so 20 years ago – he didn’t talk.”*

### **Attitudes towards ASDs in Aboriginal families and communities.**

The overwhelming attitude towards children with ASDs in Aboriginal families and communities that came through the interviews was one of love and acceptance.

*“For some reason our ancestors have sent these beautiful children to be part of our lives – we have all been chosen to be their parents.”*

*“I’ve been told by my grandmother and my mother that I’ve been picked to be (child’s) mother. (Partner’s) and my ancestors have sent him to us for a reason. Every day I believe this a little more because I’m becoming more empowered.”*

*"I want people to know I'm not ashamed."*

*"The kids all call out to him in town – and it makes my other kids see that he's accepted."*

*"That's just my son – we love him – he's not a handful"*

*"This is how he is – we love him for how he is".*

*" There are so many things I love about (child)".*

*"Now I think 'don't feel sorry for him because he's not sorry for himself.'*

One response from family and community that was reported was that *" the child is just different or will grow out of it – or the child is special."*

Some families reported observing people keeping their distance from them or their child.

*" Other parents were a bit stand-offish to start with him - being different it's hard to break through."*

*" I felt very abandoned by friends in the beginning – either that or I alienated myself from them. My time couldn't be spent sitting down having a cup of tea and a yarn. I thought – what have they got in common with me? I felt alienated from the community when I was going through the really bad stage – no one was coming to say, 'is everything alright?'"*

*" Some Indigenous families don't want to take on the extra burden, therefore they ignore it."*

### **Paths to diagnosis**

The parents interviewed had different paths to getting a diagnosis of ASD. The paths taken included going privately to a paediatrician due to frequent seizures, going privately to a speech therapist and being referred to a paediatrician through the GP at the Aboriginal Medical Service.

Some parents had difficulties getting a diagnosis of autism.

*"I'd explain his behaviour and the doctor would say 'he can't be autistic"*

One parent told a story of an earlier injustice that had made her angry and led to her being less passive now and a stronger advocate for her child.

*" I was a passive person before – when something happens that's wrong we need to let people know it's not right."*

Parents knew there was something about their child that needed assessing.

*"We know something's wrong - it's just getting the right people to listen."*

## **Feelings after diagnosis**

Some parents reported feeling 'devastated' and a period of grieving after diagnosis that continues to resurface now.

*"I didn't even know what Autism was. I remember I had days in the town library crying my eyes out."*

*"My parents went through a lot of grieving – 'why our boy?'"*

*"For a long time I went through this thing of why me? why my boy? When I see so many kids not as loved as he is. I grieved for what I knew could and should have been his life as a young black man."*

*"I grieve for him all the time but you've just got to snap out of it."*

*"Mostly you feel sad because you can imagine how he feels."*

Concern was expressed about what will happen after the parents are no longer able to care for the child due to old age or passing away. This is particularly an issue for older women (for example aunts or grandmothers) who are caring for a child.

Parents generally described feeling relieved to get a diagnosis, seeing the diagnosis as the first step towards getting help for their child.

*"Relieved that we can work on it now."*

*"After diagnosis I felt: 'Its over now – now we can get him help', but later on I felt guilty because I hadn't done anything earlier."*

## **Family and community issues**

It needs to be recognised that the person parenting an Aboriginal and Torres Strait Islander child with an ASD is frequently someone from the extended family for example an aunt or grandmother.

*"We don't think I'm an aunty to these children – I think they are my children."*

There are particular demands on primary carers who are older (such as grandmothers) and who care for a child who is very time consuming and challenging. Older carers also have more pressing concerns about who will care for the child when they are no longer able or have passed away.

Being part of a supportive Aboriginal or Torres Strait Islander extended family can make it easier to bring up a child with autism because of the love and help of family and community members.

*“The strongest thing about Aboriginals is our support system. I don’t think we’d be able to cope without it.”*

Lack of understanding about ASDs may lead to the child and family being misunderstood, criticised for their parenting or left out of family and community activities.

Lack of support services and skills within communities leads to some families not getting enough respite care.

*“He’s too strong for my mother to help me with him now.”*

Generally families of children with an ASD give a high priority to keeping the child involved with their community

*“I’ve always made it a point for my community to know of (child) and that he’s a special boy in the community.”*

One parent stressed that she sees her community as having a ‘special responsibility’ towards her child.

*“I want our community to connect with him because he doesn’t know how to connect with them.”*

*“(Child’s) got just as much right to be in the community as anyone else – he doesn’t have to adjust to them, they have to adjust to him.”*

### **Awareness of the value of Early Intervention**

Parents interviewed were generally aware that early intervention for children with an ASD was important. There was also awareness among this group of parents that, unlike them, many Aboriginal families would not be aware of how important early intervention is for children with autism.

One parent was aware that her son had missed out on getting adequate early intervention services because of living too far away from a specialist school and because of being unable to afford the school’s fees. She was aware of a *“big gap between which kids get the behavioural intervention programs and which don’t.”*

### **Support from Aboriginal and Torres Strait Islander child care centres and other Aboriginal services.**

*Culturally appropriate* service provision, particularly respite care and early intervention was rare for the group of parents interviewed but very well appreciated when available. One parent reported feeling her child was ‘safe’ and ‘made one of the family’ when respite care is within an Aboriginal community setting.

*“Its totally different when your care worker is one of your own – they make the kid one of the family and look out for them. Its totally different.”*

*“There should be more culturally specific services for our kids. People who work in services need to be aware of where we’re coming from e.g. why we need an Aboriginal care worker, why we need emergency respite when there’s a funeral so we can represent our family.”*

The need for culturally appropriate adult services for the future was also highlighted.

*“I worry what’s going to happen to my boy when he turns 18. If he lives in a group home it needs to be one where his family can come and volunteer and he can be with his special needs cousins he’s grown up with.”*

Parents strongly supported staff at Aboriginal services such as child care services learning about ASDs and being trained to help identify them and work with children in the best way. (One paediatrician gave the child care centre staff a survey about the child to complete before reaching the diagnosis of autism.)

### **Support from mainstream medical, early intervention services and children’s services**

Aboriginal and Torres Strait Islander parents with children with autism reported mixed experiences with mainstream medical, early intervention services and children’s services such as child care.

Some mainstream services are clearly providing a good service to Aboriginal families.

*“The kindy (mainstream) has been very very helpful.”*

Other mainstream services had negative reports.

*“They don’t understand where I’m coming from.”*

*“There’s no Aboriginal worker in (agency) that could do for (son). The workers there just complain about him.”*

*“The years from diagnosis to five years were very hard – no one gives you any help, no ones coming to you and telling you what’s out there.”*

### **Barriers to Diagnosis**

Aboriginal and Torres Strait Islander families face many barriers to a child being diagnosed early and receiving appropriate early intervention support. The barriers discussed included cost, location, transport and lack of responsiveness to the cultural needs of families by mainstream services. These barriers do not seem to be generally well understood by mainstream service providers.

*“There are so many barriers for me as an Aboriginal mother to get the best for my boy.”*

Barriers were not experienced by all parents interviewed. One parent from a metropolitan area reported no difficulties with accessing services.

*“I had no difficulty getting in to services- I knew what he had therefore knew what to do. I knew there were lots of services.”*

Problems were experienced in rural towns and although families living in remote locations were not interviewed, the view of service providers participating in the Alice Springs workshop was that all barriers experienced by rural Aboriginal and Torres Strait Islander families would be greatly magnified for families living in remote communities.

A feeling that *“the system is set up for white kids”* was expressed. This was seen as a problem both from the point of view of simply accessing a service and also from the point of view of accessing culturally appropriate services.

*“Everything’s gone mainstream and we’re losing our identities – we need to overcome our health hurdles before they mainstream us all.”*

### **Culture and ASDs**

Families value bringing up their children with an ASD ‘strong in culture’ and try to include them in cultural activities and cultural learning.

*“I involve him in cultural things but keep it at levels that he’s comfortable with.”*

*“We use language words with (child) and he understands some of them e.g. ‘Yunnay’ –We’re going”*

*“His father is always talking to him about the stars and animals in Kamillaroi language and (child) responds to these words.”*

Cultural life and cultural ways of doing things incorporate challenges for the parents and families of children with an ASD.

*“When he’s asked to give nan or aunties a cuddle he’ll do it but there’s no feeling in it. They just grab him anyway, but he hates it.”*

*“(Child) wouldn’t join a dance group that teaches little ones – or if he did join it he wouldn’t have the paint on his body. We were shocked one day when he allowed a little bit of paint on his face.”*

*“We’ll probably never get to see him do traditional dance.”*

*“Biggest thing for us is state-wide footy carnivals but (child) may never participate. Culturally these are very important but he shows no interest in joining a team.”*

*“I couldn’t tell you how many funerals (partner) and I have missed. That’s our people’s way of showing respect – making sure you’re at funerals.”*

Families reported having to reduce involvement of the extended family in their lives in order to meet the needs of the child with autism.

*“We’ve has to cut back the time we have out nieces in the house. (Child) is a big boy now and needs his privacy at home – he might strip himself and run out of his room.”*

*“My family understands that things have to be a certain way for (child). We can’t have a big mob in the house all the time. At night the lights have to be out and TV turned off.”*

### **Racism and ASDs**

Aboriginal and Torres Strait Islander families with children with an ASD worry that their children’s behaviour might result in they the parents being negatively judged for who they are and where they come from.

*“ We get bad publicity when kids behave bad – they think its where they’re from.”*

Aboriginal and Torres Strait Islander families with children with an ASD also worry about how well the child will be accepted by mainstream Australian society given low levels of acceptance of disability, and racism towards Aboriginal and Torres Strait Islander people.

*“ A Euro child with autism would be accepted more than what a little Aboriginal child would be.”*

### **SERVICE PROVIDER INTERVIEWS**

SNAICC also consulted with four Early Intervention agencies that work with Aboriginal and Islander families and also with 88 participants (predominantly child care centre staff) at the six Aboriginal and Islander Child Care Centre Early Days workshops. SNAICC was also discussed issues at a national meeting of Autism Advisors in June 2010 to which FaHCSIA invited SNAICC to do a presentation in June. The section below summarises the findings of these consultations.

#### **What works well to support families in the time before a child is diagnosed?**

-Going slowly. *“Once children are identified by child care staff as having a problem, it’s a slow process and we go at the family’s pace otherwise we might lose them.”*

*“ Slow walk beside the family to achieve the same goals.”*

*“ If we push too hard we’ll lose the family.”*

-Regular meetings: *“ Families need to hear the information lots of times to reinforce what’s being said.”*

-Sensitivity: *“Some families will be lost if the word ‘autism ’ is used too early and some families are reluctant to be labelled with the word ‘autism’.*

-Hands on support for the family. An early intervention worker commented that she made the appointment at the paediatrician for the family and was on hand to support the family after the diagnosis.

-Find an acceptable entry point to discuss the child's developmental progress with the family e.g. 'what would you expect the child should be doing at this stage? What would you expect your child to be doing in six months time?'

### **Barriers to achieving a diagnosis for Aboriginal and Torres Strait Islander children with Autism.**

-Fear of the child being removed. The 100 year history of forced Aboriginal and Torres Strait Islander child removals (the Stolen Generations) means that many families today are reluctant to expose themselves or their child to anyone such as a mainstream medical service who may make a child protection report.

-Transport - managing to get to appointments with other children as well as the child with Autism can be very difficult and a real barrier for families.

- Lack of assessment services. This project received feedback that services that are able to assess a child are very rare in rural and remote areas. The Northern Territory was highlighted as a particular problem but other rural areas reported a lack of assessment and intervention options as major issue.

*"In the Riverlands we not only have to go to Adelaide (three hours drive), we have waited up to 12 months for an assessment."*

-Housing instability – may make it hard for some families to keep regular appointments.

-Parents often have health issues of their own to deal with (both physical health issues and mental health issues).

-Lack of knowledge of child development may lead to family not realising anything is wrong.

-Families may be embarrassed or ashamed because they feel that something they have done (e.g. alcohol use) may have caused the Autism or feel that professionals will think this.

-Language difficulties – English may not be the first language and literacy levels may be low.

-Families may not have access to the Internet – this should not be assumed.

*"A lot of people are afraid, I took my child to hospital for an ear infection and the hospital called protective services."*

### **How to be more sensitive to cultural issues.**

The following suggestions were made about how workers can be more culturally sensitive when trying to support Aboriginal and Torres Strait Islander families bringing up children with an ASD:

-Recognise widespread genuine fear within Aboriginal and Torres Strait Islander communities of protective services getting involved. No family has been untouched by Stolen Generations policies and families fear there is a risk of child protection involvement if they discuss their child's difficulties or their own parenting difficulties.

- Provide training in cultural competency to all Autism Advisors and Early Intervention workers.

-Recognise that invitations to attend information sessions or assessments should be extended to anyone in the extended family or community that the parents want to invite.

-Recognise that shame and lack of understanding about the causes of Autism may be issues for some families

*"I've done something wrong or it's my fault leads to reluctance to do something about it."*

-Recognise that resistance to labelling may be an issue for some families:

*"It's about white people doing the labelling and with this are issues of power. This labelling is on top of all the other labels being given to Aboriginal folk."*

-Recognise that reluctance to seek diagnosis or labelling may be because of high levels of acceptance of the child the way he or she is.

*"In the Koorie community anyone who is different is cherished. They don't need a label – they are cherished anyway."*

### **How to support Aboriginal and Torres Strait Islander families with a child with an ASD.**

-The legacy of the Stolen Generations means that fear of child removal is very real for Aboriginal and Torres Strait Islander families – never dismiss these concerns lightly.

-Focus on building good relationships. One way of doing this is to engage trusted Aboriginal or Torres Strait Islander facilitators to introduce the Autism Advisor or early intervention worker to the family. Trusted Aboriginal or Torres Strait Islander facilitators can also play a valuable role in deciphering the language that professionals use.

*"10 out of 10 is about building good relationships between the parents and the centre."*

*"Have a support person to help explain the language and assist in literacy. Don't let the doctors talk over the parents."*

-Provide information or services within Aboriginal and Torres Strait Islander services e.g. Multi-functional Aboriginal Children's Services (MACS) or other trusted Aboriginal or Torres Strait Islander venues. Again using a facilitator trusted by the centre is the best way to contact centres and organise the provision of services/ interventions to a child and their family

-Provide transport to enable families to access services.

- Provide cost free services.
- Do not assume that families can afford to pay for services up front and then be reimbursed later.
- Provide of a range of services under one roof.
- Invite family network e.g. aunts, uncles, grand-parents, anyone the family would like to invite.
- Provide Internet access to keep families informed and in touch with support groups, or service providers.
- Provide outreach services with trusted local Aboriginal staff.
- Be respectful of families' feelings – some are open about ASDs but some have difficulty coping with the idea of Autism or feel angry.
- Approach families with smaller issues or concerns (eg speech problems) at any one time – don't flood the parents with too many issues all at once.
- Develop a good understanding of the child's behavioural issues and refrain from being judgemental.
- Develop an understanding of what issues there are for the child *and* the family.
- Recognise that not all families have good support structures.
- Recognise that some families' lives lack structure, routine and consistency and that this may make it difficult to implement set routines for the child in the home.
- Recognise that conversely many families *will* successfully be able to implement behaviour management strategies at home.
- Recognise that not all families will have the ability to provide respite care from within the family network – particularly if dealing with the child's behaviour requires special skills.

**Role of Aboriginal and Torres Strait Islander child care services.**

The workers interviewed described a generally high level of acceptance of children with disabilities at MACS and other Aboriginal and Torres Strait Islander child care centres.

*"They are part of a centre where whoever comes in the door is just part of the group. There is love and acceptance for difference. Children are accepted for who they are."*

*"Centres often consider the question: 'is there more we could be doing for the child.'"*

*“If staff have to support the family to get children to their appointments then this is what they do.”*

*“Important for staff to have good understanding of Autism so they can explain it to families e.g. explaining that makaton (sign language) promotes verbal communication rather than holding it back.”*

Ensure that Aboriginal and Torres Strait Islander child care services are not out of pocket if they have a child with an ASD that requires an additional carer – ensure that all costs are fully met.

## **Literature Review**

SNAICC chose to supplement these consultation findings with findings from relevant literature.

Prior to commencing this project, SNAICC was not aware of previous research on Aboriginal and Torres Strait Islander perspectives on ASDs and the experiences of Aboriginal and Torres Strait Islander families parenting children with Autism. Research of this kind has not been identified by this project and may not exist.

Two projects of relevance are however worth mentioning. The first is *Māori Perspectives of Autistic Spectrum Disorder* by Jill Bevan-Brown<sup>2</sup> Ministry of Education New Zealand 2004.

This report was based on face to face interviews with the parents of nineteen Māori children. The reports findings were as follows:

-There was strong support for having a person visit parents, sit down with them to explain what ASD was, what services and entitlements were available and to assist them in obtaining these.

-Knowledge of ASD varied amongst parents, however most had a good understanding and six were considered to be experts who had attended conferences, read widely, sought out relevant research and were active members of various parent organisations. The world wide web played a major role in informing parents and was used by 11 out of 17 families.

-Parents varied in their desire for cultural input into their child’s education and service provision. This ranged from substantial input to nothing at all.

-Impairments associated with ASD were identified as hindering children’s involvement in cultural activities such as kapa haka (cultural dance), learning te reo (Māori language) and staying on the marae (meeting area/ sacred place).

-Children were also disadvantaged because of difficulties experienced in culturally valued behaviours and practices such as group activities and whakawhanaungatanga (establishing relationships).

-Māori-medium education and Māori services were seen to hold both advantages and disadvantages for children with ASD. On one hand, the cultural content, wairua (spirit) and inclusive, supportive attitude of staff and children in educational facilities and the friendly,

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<sup>222</sup> Bevan – Brown J. *Māori Perspectives of Autistic Spectrum Disorder* Ministry of Education New Zealand 2004.

approachable style of Māori service providers were seen as beneficial. On the other hand, there was considerable concern about the lack of ASD expertise amongst some Māori staff and service providers.

-Considerable variation existed in the degree to which parents received whānau (extended family) support. This ranged from 24/7 help to none at all. It was quite typical for support to vary within whānau. Also typical was a general lack of understanding of ASD amongst whānau members. Siblings were reported to be helpful, protective, embarrassed, annoyed and sometimes “left out” as a result of having a brother or sister with ASD.

-Parents described a wide range of helpful people and services.

-Parents also described a variety of barriers they had encountered. These included: a shortage of information, services, funding and qualified personnel; difficulty accessing services; assessment, organisational, system and procedural hassles; financial strain; personal and family stress; detrimental attitudes of professionals and society in general; and a lack of knowledge of ASD amongst professionals leading to inappropriate, ineffective programmes and provisions and incorrect decisions.

-Parents’ dreams for their children’s future were for them to be happy and to live as independently as possible.

Some recommendations from the project include:

- Develop user-friendly, culturally appropriate administrative and funding procedures;
- Adopt friendly, personal approaches to service provision which include providing information to parents, assisting them to access resources and entitlements, and supporting them during transition periods such as beginning, changing and leaving school.
- Increase teachers’ and other professionals’ knowledge of ASD and Māoritanga (Māori cultural practices and beliefs) to enable them to provide culturally appropriate, effective programmes and services;
- Upskill personnel employed in existing Māori provisions and increase and expand these services;
- Increase the bicultural and bilingual expertise of personnel in mainstream services;
- Listen to and be guided by parents.

A second report relevant to this project is *Aboriginal People with Disabilities Getting Services Right* Government of Western Australia Disability Services Commission (2006).<sup>3</sup> This publication describes itself as a ‘booklet for agencies wanting to develop services for Aboriginal people with disabilities and to make current services more responsive to Aboriginal people.’ The booklet is based on based on ‘yarning’ with 319 people living in metropolitan, rural and remote areas of

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<sup>3</sup> Government of Western Australia Disability Services Commission *Aboriginal People with Disabilities Getting Services Right* 2006.

Western Australia during 2003 and 2004 - 97 Aboriginal people with disabilities or family members and 222 Aboriginal and non- Aboriginal agency staff.

Relevant findings in this booklet include:

-Aboriginal people with disabilities, their families and carers need access to disability information and services which they can understand and relate to, and which respects and integrates Aboriginal culture.

-Aboriginal people are, in general, less familiar with the term 'disability' and the way in which it is understood in Western culture.

-Some Aboriginal people maintain cultural and mythological beliefs about the reasons for a disability occurring and it is important that service providers understand this.

-These causes do not appear to result in discrimination against the family or child.

-Aboriginal families consider themselves to be more accepting and supportive of family members who have a disability than are non-Aboriginal people. People with disabilities were reported to be included within their extended families and able to assume kinship roles and responsibilities where possible.

-Aboriginal families may not as readily recognise that a person has a disability or the way in which support and services could assist in fostering health, skill development and independence. This is considered to be partly due to the natural inclusion of Aboriginal people with disabilities in community life where disabilities are not emphasised, and partly due to lack of information about the Western understanding of disabilities.

-Taking time to understand a local Aboriginal perspective to disability is an essential part of developing services or supports in partnership with individual, family or community, that are culturally relevant, acceptable and likely to be effective.

-Aboriginal people want more information about different types of disabilities and the range of services available to provide support.

-Some Aboriginal people feel that there is a stigma associated with being registered with a disability services agency and need to know of alternative supports. Others have a misconception that some services are only available to non-Aboriginal people.

-Information needs to be made available in different ways. A number of Aboriginal people are unable to read English and prefer alternatives to printed books and pamphlets, including radio, television and informal meetings. Where printed information is used it should contain plain English, no jargon, and feature visual information using familiar environments and Aboriginal people.

-Agencies must work alongside Aboriginal communities and agencies to develop effective information strategies for Aboriginal families and agencies.

-Many Aboriginal people are reluctant and, even afraid, to ask for information and assistance from agencies due to negative experiences with past government policies and practices.

-Many Aboriginal families live in relative poverty and find it difficult to cope with the additional costs of caring for a person with a disability.

-Many Aboriginal people experience greater vulnerability, greater avoidance from non-Aboriginal people and less support due to being Aboriginal and having a disability.

### **Good Service Provision: Case Studies**

Below are two case studies that illustrate successful partnerships between Aboriginal and Torres Strait Islander organisations and non-Indigenous services that provide services to Aboriginal and Torres Strait Islander children and families.

**1. Little Yarns** – A model that helps identify and support Aboriginal and Torres Strait Islander children with speech and language development.

Little Yarns is a joint project between Awabakal Early Childhood Services (a MACS centre) and First Chance Inc. The project is a four-year pilot aimed at providing prevention and early intervention for children within the local Aboriginal community in the Newcastle region in NSW. The team consists of three early intervention workers, one speech pathologist and a cultural advisor. The project steering committee is the directors of the Awabakal childcare service.

The guiding principles of the project focus on:

- Building relationships with both the staff and the families
- Utilising existing community relationships and community based services
- Seeing children in groups rather than singling them out
- Utilising a flexible and positive approach

The program acknowledges that different families will hear information in different ways. The process of how information is shared includes:

- Working collaboratively with the trusted 'gatekeeper' who assists in deciphering the language that professionals use.
- The inclusion of the extended family.
- Support for the family prior to, during and after the diagnosis.
- Flexibility and understanding that for many families the process will take time – 'a slow walk beside the family to achieve the same goals'
- 'With love and acceptance, the staff's job is to also help the child meet their potential'

### **2. Darebin Community Health: Building the bridge between mainstream health and Indigenous education.**

After a ten year relationship in 2009 a partnership was formalized between the mainstream paediatric allied health service based at Darebin Community Health (DCH), and Yappera

Children's Service Yappera is a multifunctional Aboriginal Children's Service that is community managed which provides long day care, occasional care and kindergarten program for Aboriginal and Torres Strait Islander children. Both of these services are located in metropolitan Melbourne in an area that has the highest number of residents identifying as Aboriginal and Torres Strait Islander living within metropolitan Melbourne.

The goal of the partnership is to provide Aboriginal and Torres Strait Islander children access to allied health services in a culturally accepted setting with support and liaison from an Aboriginal Liaison Officer. DCH has a policy that stipulates that Indigenous children and families have priority of access to services. They also provide outreach services to Aboriginal and Torres Strait Islander children and families

The model of service includes:

- Building trust and relationships with Yappera staff and families to facilitate timely access to services to support child development e.g. speech therapy.
- One to one weekly outreach clinical services offered by speech pathologist, occupational therapist, physiotherapist & Aboriginal Liaison Officer.
- Support to Yappera staff to undertake comprehensive assessment to support educational development including relevant referrals to address identified issues.
- Support with program development to achieve optimal key developmental milestones in preparation for transition to school.
- Building capacity of the mainstream organisation to work with Indigenous communities.

DCH provides:

- Support and training to the staff.
- Direct service, intervention and support to families / children attending Yappera.

Yappera provides:

- Culturally safe setting.
- Support for DCH staff to work in a culturally sensitive way.
- Opportunity to work together with families.
- Information to community about relevant programs to children and families.
- Referrals.
- Support and confidence to parents/carers to access specialist & support services.
- Commitment and relationship building over a long period of time.

The longevity of the partnership is due to both organisations seeing the value of working together and the adoption of a flexible and respectful approach.

## **SNAICC WEBSITE FOCUS SITE**

Jane Bevan Brown's research (*Maori perspectives of Autism Spectrum Disorder*) found that the world wide web played a major role in informing parents.<sup>4</sup>

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<sup>4</sup> Bevan – Brown J. *Māori Perspectives of Autistic Spectrum Disorder* Ministry of Education New Zealand 2004. pxi

The establishment of significant web based information and support for parents was beyond the scope of this project however a 'focus site' on the SNAICC web site providing information about Aboriginal and Islander perspectives and experiences raising children with ASDs was established. The site provides information about this project and its findings, a story by one of the parent's interviewed and a link to the Early Days website <http://www.earlydays.net.au/> and raising Children Network Children with Autism Spectrum Disorder page. [http://raisingchildren.net.au/children\\_with\\_autism/children\\_with\\_autism\\_landing.html](http://raisingchildren.net.au/children_with_autism/children_with_autism_landing.html)

There are many other locations on the web that provide information about Autism for families, however none are Aboriginal and Torres Strait Islander specific. SNAICC considers that there is great scope to support Aboriginal and Torres Strait Islander families raising children with Autism via Internet based support. Two international examples provide examples of the potential of the Internet to provide culturally relevant information to Aboriginal and Torres Strait Islander families.

#### *Autism in Black*

The web site Autism in Black <http://autisminblack.com/> provides information about Autism, African American issues in relation to children with autism and advice for the African American community members about "How can we take action to get the most for our child or to help someone who has a child with autism?"

The front page of the web site reads as follows:

"Raising a child with Autism can be difficult for anyone, however in the Black community there are additional challenges that may affect us. Although early intervention is key, African American children with autism are one to two years older than white children before they're even diagnosed. This web site will explore some of the reasons for this and also provide suggestions to correct these issues. We will include links to web sites, articles, and research regarding autism and the African American community."

This site is organized into three different categories:

- Medical issues
- Educational issues
- Cultural issues

It provides suggested solutions to combat disparities in diagnosis age between black and white American children.

#### *Aboriginal Autism Facebook Group*

Aboriginal Autism Facebook Group is a web based support group for Canadian Aboriginal (First Nations) families. The site provides a forum for families to seek and share information and a place for providers of support and information to reach First Nations families. The group has over 300 members and describes itself as follows:

“My child is living with a diagnosis of Autism/Pervasive Developmental Disorder. As First Nation people, we have found that there are not many Autism or special needs resources, groups or services that recognize and support our unique cultures, languages, beliefs, practices and communities.

As most First Nation people know, there are no formal supports on reserve to assist us with parenting our "special needs" children.

It's up to parents, families and communities to provide for their children in the best way that they can.

Perhaps those of us who are caregivers or families of people with Autism can come together to discuss our common challenges and maybe create our own resources, groups and supports. If you know of anyone who may be interested in this group please pass on the message.”

SNAICC’s research so far has identified that Aboriginal and Torres Strait Islander families raising children with ASDs are not members of formal parent support groups and may not know other Aboriginal and Torres Strait Islander families raising children with ASDs with whom they can share information and talk things over. Although some Aboriginal MyTime groups have been established in WA and Victoria, these groups cater for families with a variety of disabilities and chronic health conditions and are not specifically for Aboriginal parents raising children with autism. All families interviewed indicated that an Australian Aboriginal Autism Facebook group or something similar would be a valuable initiative.

### **SNAICC CONFERENCE PRESENTATION**

A workshop on this project was held at the 2010 SNAICC Conference For Our Children: Local strengths, National Challenges Ampe Anwernekenheke: Rlterrke Akwete Aneye 27-29 July in Alice Springs. The workshop include presentations from PRC, SNAICC and two of the Aboriginal parents interviewed for the project. Approximately 120 people registered for the workshop.

Workshop participants gave very good feed back about the content of the workshop and in particular the presentations of the two Aboriginal parents. One evaluation form indicated SNAICC should “reach out more to raise awareness for parents about the support in existence for parents and families with children with Autism Spectrum Disorder”.

### **CULTURAL COMPETENCE**

SNAICC considers that for anyone involved in providing information or services to Aboriginal and Torres Strait Islander families of children with an ASD, cultural competence should be demonstrated by:

-Adequately recognising the role of extended families in raising children. Aboriginal and Torres Strait Islander Family members involved in children’s lives, and helping to raise them, commonly include grandparents, aunts, uncles, cousins, nieces and nephews and members of the community who are considered to be family. Aboriginal and Torres Strait Islander families are often larger than white families and provide connections that are a

source of great strength and support.

-Adequately recognising the diversity of Aboriginal and Torres Strait Islander lifestyles and circumstances. The lives of Aboriginal families living in metropolitan areas differs from those in rural towns and differs markedly from those in remote communities. There are also wide variations in languages spoken, cultural beliefs, education levels, income and housing. It is useful to think of the Aboriginal and Torres Strait Islander population of Australia as being as culturally diverse as the population of Europe with numerous languages spoken, lifestyles etc.

*“The population of Australia's Aboriginal and Torres Strait Islander communities is extremely diverse in its culture with many different languages spoken. Think of the Kimberly region of Western Australia ... if you travel through the Kimberly with its large Aboriginal population and the diversity of people within this region, it's just like travelling through Europe with its changing cultures and languages.”*

(Dot West, National Indigenous Media Association of Australia, Boyer Lectures 1993)

-Adequately and sensitively recognising the history of Aboriginal and Torres Strait Islander peoples lived experience since colonisation.

-Recognising the centrality of family, land and culture.

-Acknowledging that Aboriginal and Torres Strait Islander culture “is caught not taught” and that family and community are the source of an Aboriginal or Torres Strait Islander child’s culture.

-Acknowledging the continuing relevance and importance of the systematic removal of Aboriginal children (the Stolen Generations) from their families, communities, land and heritage. No family was unaffected by these policies.

-Acknowledge that Aboriginal and Torres Strait Islander children are nine times more likely to be removed from their families for child protection reasons than non-Aboriginal children<sup>5</sup> and that involvement with mainstream social welfare or medical services is of great concern to many Aboriginal people due to fear of child protection involvement.

## **DISCUSSION OF FINDINGS**

### **Mainstream Early Days Workshops**

SNAICC has reviewed the Early Days material and a member of staff and member of the SNAICC Executive Committee have attended a mainstream Early Days workshop.

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<sup>5</sup> Australian Institute of Health and Welfare *Child Protection Australia 2008–09* p 46

SNAICC does not consider that mainstream Early Days workshop can be assumed to be suitable for Aboriginal and Torres Strait Islander families. Facilitators of these workshops should be aware however that Aboriginal parents may sometimes attend. If Aboriginal and Torres Strait Islander families enrol in mainstream workshops, facilitators should:

- Be Aboriginal or Torres Strait Islander or be able to demonstrate cultural competence.
- Invite any members of extended family to join the workshop (rather than limiting attendance to parents). If the child is in out of home care the carers of the child should attend and their parents and family members should also be invited.
- Build on the knowledge of participants as per best practice adult education, but don't put them on the spot to demonstrate their knowledge to the group (culturally inappropriate)
- Include flexible questioning time.
- Use a trusted co-facilitator, preferably Aboriginal or Torres Strait Islander from the family's local community.
- Use plain English
- Offer interpreters in areas where English not language spoken at home
- Use visual presentations with lots of colour and hand outs in plain English (or translated into the appropriate language to take away).
- Consider avoiding activities which involve writing because some Aboriginal and Torres Strait Islander communities have low levels of literacy. Most if not all activities could be modified to avoid writing. If activity cannot be modified (unlikely), suggest work in pairs or groups, with only one scribe required per group.
- Use case stories / examples.
- Use videos. It would be great to have video/s with Aboriginal and Torres Strait Islander people featured.
- Allow plenty of time for discussions and activities (may involve fewer activities with longer time for each). Yarning is an evidence based and culturally appropriate methodology that cannot be contained in the kind of tight timeframes in this program.
- Provide information about local early intervention services and ideally invite them to meet the group. Putting a face to a name will encourage service access and having a chance to meet and sound them out will build trust.

**Workshops for Aboriginal and Torres Strait Islander child care centres.**

**SNAICC's view is that *Understanding Autism* workshops should be made available to all Aboriginal and Torres Strait Islander child care centres.** The workshops organised and presented within this project were enthusiastically taken up by the centres when offered and provided information that was new, interesting and valuable to child care workers and other participants. The workshop in Shepparton facilitated the introduction of the local Autism Advisor to the centre. SNAICC's view is that other Aboriginal and Torres Strait Islander child care centres would request and benefit from a workshop if the option was available.

Additional workshops for Aboriginal and Torres Strait Islander child care centres would have very important benefits for Aboriginal and Torres Strait Islander families bringing up children with ASDs and for the children themselves. These benefits include:

- Staff enabled to identify children who may have an ASD and facilitate consultations and diagnoses in partnership with the family and service providers.
- Staff enabled to better relate to children with an ASD (regardless of whether they have been diagnosed) and better meet their needs while they are at the centre.
- Staff introduced to or made aware of the local Autism Advisor and local services able to assess children or provide early intervention services

Workshops may also be welcomed at other child care services with a high level of involvement with Aboriginal and Torres Strait Islander families.

If further workshops were to be scheduled, the content of the workshops should be modified to build on the learning from this project and better meet the needs of all participants. Some changes SNAICC would recommend include:

- greater focus in the workshops on the characteristics and behaviour of children with ASDs.
- greater focus on how staff can better relate to and meet the needs of a child with an ASD in the child care setting.
- greater focus on what Early Intervention entails for a child with an ASD and the short and long term benefits of Early Intervention. The use of case studies would be valuable.
- enabling child care centre directors to attend by either scheduling workshops on days when either the centre is closed or on days when a relief director is available.

#### **Early Days Workshops for Aboriginal and Torres Strait Islander families.**

SNAICC's view is that the option of modifying the content of the mainstream Early Days workshops and using a culturally competent facilitator to deliver them to individual Aboriginal and Torres Strait Islander families or if appropriate and requested by the participants two or three Aboriginal and Torres Strait Islander families together should be developed. Participants in this project supported the proposal of information workshops that involved the child's extended family and potentially other relevant community members. The content of the workshops should be tailored to meet the needs and circumstances of families and should reflect the issues identified in this project.

The workshops should include content that assists families to better meet the needs and support the development of their child at home and discusses the pros and cons of obtaining a diagnosis and arranging Early Intervention services. The workshops should ideally include an Aboriginal or Torres Strait Islander co-facilitator or a co-facilitator from a trusted Aboriginal and Torres Strait Islander organisation. The co-facilitators role would be to encourage families to attend the workshops and to support them during the workshops by liaising between the family and the facilitator to ensure the language and content were appropriate. Fred Hollows advocated this approach for the Eye Health and Trachoma program "...the important thing about the trachoma program was Aboriginal liaison. And the reason we succeeded was we got a good lot of Aborigines working with us who would go ahead of us, tell the people what we were on about, what benefits they would gain and get the people on our side." (Fred Hollows)

### **Internet site**

An Aboriginal and Torres Strait Islander specific web site or Aboriginal and Torres Strait Islander specific section of the Early Days web site would be one way to make Early Days more inclusive of Aboriginal and Torres Strait Islander families.

Some suggested Aboriginal and Torres Strait Islander content may include:

- Details of Aboriginal and Torres Strait Islander specific workshop options.
- Quotes from Aboriginal and Torres Strait Islander parents or workers.
- Positive case studies of Aboriginal and Torres Strait Islander families going through assessment and diagnosis and early intervention with scope for families to explain their motivations and experiences.
- Positive case studies of Aboriginal and Torres Strait Islander children involved in early intervention with parents or other family members discussing their child's progress.
- Photographs of Aboriginal and Torres Strait Islander children and families.
- Links to relevant research and articles.

### **Further Research into Barriers to Diagnosis**

It was beyond the scope of this project to research in depth the many barriers Aboriginal and Torres Strait Islander families face to a child being diagnosed early and receiving appropriate early intervention support. Anecdotally, the barriers experienced by rural Aboriginal and Torres Strait Islander families appear to be much greater for families in rural areas compared to metropolitan areas and are greatly magnified for families living in remote communities. This is an area that requires further research.

### **Increasing Awareness about Autism in Aboriginal and Torres Strait Islander communities.**

Greater awareness about Autism in Aboriginal and Torres Strait Islander communities would lead to more children being diagnosed and receiving early intervention services and also

potentially result in greater community understanding of and support for children with ASDs and their families. Many Aboriginal and Torres Strait Islander families do not have Internet access and culturally appropriate non-web based resources to help support parents and community members to understand ASDs are needed. Options such as a pamphlet and story books for children have been suggested by people interviewed for this project and would in SNAICC's view be very valuable. One parent describes her vision for story books such as "Why my brother is different" and "Why my sister is different" which would provide simple information for children but also be useful for other members of the community.

## **RECOMMENDATIONS**

### **A. Recommendations for the Parenting Research Centre**

1. That the PRC develop a culturally appropriate Aboriginal and Torres Strait Islander specific section of the Early Days web site.
2. That facilitators of Early Days workshops be Aboriginal or Torres Strait Islander or be required to demonstrate that they have had Aboriginal and Torres Strait Islander specific cultural competence training or otherwise achieved competence in this area.
3. That the PRC offer Early Days workshops for individual Aboriginal and Torres Strait Islander families, inviting extended family and using a culturally competent facilitator. A local co-facilitator should also be used to liaise between the facilitator and the family.
4. That the content of the Early Days workshops for individual Aboriginal and Torres Strait Islander families be tailored to meet the needs and circumstances of families and should reflect the issues identified in this project.

### **B. Recommendations for SNAICC**

1. That SNAICC maintain information about autism, the outcomes of this project and the Early Days workshops on its web site.

### **C. Recommendations for the Commonwealth Government**

1. That the Commonwealth Government fund Aboriginal and Torres Strait Islander specific cultural competence training for all Autism Advisors
2. That the Commonwealth Government make funding available to enable all Aboriginal and Torres Strait Islander child care services to be offered *Understanding Autism* workshops.
3. That the *Understanding Autism* workshops at Aboriginal and Torres Strait Islander child care services include local Autism Advisors as a way of linking the Autism Advisors in with Aboriginal and Torres Strait Islander communities.
4. That the content of further *Understanding Autism* workshops be modified in consultations with SNAICC to ensure they better meet the needs of all participants.

5. That the Commonwealth Government fund research into the barriers which may prevent Aboriginal and Torres Strait Islander families seeking a diagnosis and accessing early intervention services.

6. That the Commonwealth Government fund a range of initiatives to increase awareness of Autism in Aboriginal and Torres Strait Islander communities including culturally appropriate pamphlets and story books for children.

## **Attachment 1.**

### **8 Priorities for Aboriginal and Torres Strait Islander Children and Families Secretariat of National Aboriginal and Islander Child Care Inc. (2009)**

#### **Support Families to Care for Aboriginal and Torres Strait Islander Children**

Aboriginal and Torres Strait Islander families provide children with a wonderful childhood that is enriched by family connections and cultural identity. Services engaging with Aboriginal and Torres Strait Islander families should aim to build on existing family strengths to assist families to build healthy relationships to care for themselves and their children. Child care, healing services, parenting services, housing programs and employment program are examples of the types of support that families need to provide children with a happy childhood that will be the foundation for their future success in life.

“Family is important because it holds for you the past and the future”. (SW)

#### **Value and Respect Aboriginal and Torres Strait Islander Culture**

Cultural identity and connection to family, community and country/land are the birth right of every Aboriginal and Torres Strait Islander child and what they need to prosper. Aboriginal and Torres Strait Islander children will grow, learn and excel when their cultural needs are met valued and respected at home, school, child care and throughout all aspects of their lives.

“If Aboriginal and Torres Strait Islander children know their culture is valued, they will know they are valued. “ (GA)

#### **Healing and Reparations for the Stolen Generations**

The National Apology to the Stolen Generations on 13 February 2008 was an important step in acknowledging the wrongs done to members of the Stolen Generations, their families and all Aboriginal and Torres Strait Islander people. Governments must acknowledge now that because injustice was inflicted compensation is required. Services to heal, reconnect and preserve families and prevent the removal of children in this and future generations are also essential and must be provided.

#### **Self Determination in Child Protection**

Self determination in child protection is a right. Recognising that Aboriginal and Torres Strait Islander communities are best placed to make informed decisions about the safety, well being and protection needs of Aboriginal and Torres Strait Islander children ensures self determination. Decision makers in child protection need strong trusting relationships with

families and communities to ensure that decisions are well informed. Evidence shows that community based models of child protection offer the best option for protecting children. Appropriate family and community members should be closely involved in all decisions regarding children's safety and protection to ensure risk and alternative care options are appropriately assessed. Each community must develop and run holistic community based child and family welfare services child protection service models that meet that community's needs and capacities.

### **Thrive by Five with Culture Alive**

Meeting children's health, development and cultural needs through programs that value learning and respect for culture is the best way to ensure improvements in Aboriginal and Torres Strait Islander children's long term well being and educational achievements. A confident ready-to-learn Aboriginal or Torres Strait Islander child starting school is one who is healthy, has strong family bonds, who knows and is proud of his or her Aboriginal or Torres Strait Islander culture and who has participated in a quality early learning program. A high quality early learning program is one that has supported the child to identify with and feel proud of his or her Aboriginal or Torres Strait Islander culture. This support must continue through their school years to ensure their continued confidence and success.

### **Real Results take Real Planning**

The future for Aboriginal and Torres Strait Islander people must be made by Aboriginal and Torres Strait Islander people. Plans only improve people's lives when they have been developed in close consultation with those people and include clear short, medium and long term outcomes that are properly funded, monitored and reported against. A National Action Plan for Aboriginal and Torres Strait Islander children's welfare and development which guides initiatives and programs of the federal government and all states and territories must be developed.

### **Building Capacity Builds Communities**

Aboriginal and Torres Strait Islander people know best what their children, young people and communities need and want. The role of governments is to support and sustain the ability of Aboriginal and Torres Strait Islander individuals and organisations to work in a culturally sound way that will improve people's health and education, strengthen families, improve connections to culture and build strong Aboriginal and Torres Strait Islander communities. Across all areas of the community sector governments need to work more flexibly and supportively with Aboriginal and Torres Strait Islander agencies. Rather than governments prescribing what local agencies do they should support them to meet local needs.

### **Hope Wealth and Prosperity for Our Children**

All Aboriginal and Torres Strait Islander children, wherever they live, should enjoy a childhood that encourages them to aim high and explore all of life's opportunities. They should be encouraged to dream like other kids of a happy and prosperous life and be supported to realise their dreams. Each and every Aboriginal and Torres Strait Islander child should feel safe in their

homes and communities, feel proud of their heritage and culture and have health care and educational opportunities available to other Australian children. This will enable Aboriginal and Torres Strait Islander children to share in and contribute to the wealth and prosperity of their nation.

“You give children hope by giving their families hope, by empowering families and by having faith in them that they can do great things.” (DK)

**Attachment 2.**

**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 his 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 started 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 in to 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 e-mail 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 the 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 un-co-operative 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 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 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 vegetables. 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 hyper-activity, 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 know that I've been chosen by my ancestors to be Murri's mother. My mother and father always remind 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.