

Early Days Workshops:

Supporting Aboriginal and Torres Strait Islander families raising children with an Autism Spectrum Disorder.

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What is Autism?

The term Autism Spectrum Disorder (ASD) includes:

- Autistic Disorder (autism)
- Asperger's Disorder (Asperger's Syndrome)
- Pervasive Developmental Disorder Not otherwise specified (PDD-NOS).



How does Autism impact on children?

ASD impacts on three main areas of child development:

- RELATING TO OTHERS
 - getting along and interacting with other people
- COMMUNICATION AND LANGUAGE
 - communicating with, and understanding, other people
- BEHAVIOUR
 - repetitive behaviour and changes in routines. Intense interests.



How common is Autism?

- Approximately 1 in every 150 children
- Incidence of ASD has increased
Increased awareness and changes to the way ASDs are diagnosed
- ASD is not a rare condition.
- It affects children from all cultures and backgrounds.



What causes Autism?

The exact causes of ASD are not known.

To date, there are no known environmental or outside influences that cause ASD.

It is likely there are multiple causes.

ASD is a lifelong condition and there is no cure.



What do we know about Autism?

- It's not because of how kids are raised
- Research suggests the brains of children with ASD develop differently
- We know that genetics plays a role
- It can run in families
- More boys are affected than girls



What can we do to help children with Autism?

Early intervention results in the best outcomes when:

- It focuses on the areas that are affected by autism (communication, social interaction and behaviour)
- Families are supported.

The earlier, the better.



What Early Days has done already

Workshops for MAC centres and IPSU staff:

Alice Springs, NT	Central Australian Aboriginal Congress, Ampe Kenhe Apmere MACS centre
Cherbourg, QLD	Gundoo MACS centre and IPSU Queensland
Wollongong, NSW	Noogaleek Children's Centre (Wollongong) Gujaga MACS (La Perouse) Oorunga Wandarrah MACS (Campbelltown) Gudjahgahmiamia Wreck Bay (ACT) Noah's Ark (Nowra)
Broome, WA	Jalgurr Guwan MACS centre and Broome Primary School
Adelaide, SA	12 MACS and other Aboriginal Early Childhood services
Shepparton, VIC	??



What Early Days will do over the next 12 months

- Provide workshops nationally for mothers, fathers and other family carers of young children with ASD (up to 6 yrs)
- Give families and carers the information and skills they need to support their child's development and access local services.
- Provide workshops free of charge where families live.

Workshops are designed for families who:

- Have recently had a child diagnosed with an ASD
- Are going through assessment/diagnosis process



How can families access an Early Days workshop?

- You can contact us on their behalf
- Families can contact us directly
- We are running workshops from July 2010- June 2011



Children with Autism Spectrum Disorder

 **learning about autism**

 **guide to therapies**

 **service pathfinder**

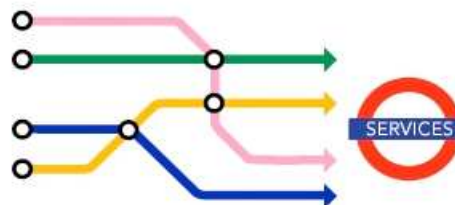
 **parent forums**



Navigating the service system

Our interactive Autism Service Pathfinder can help you find and access available services and resources for you and your child.

go



Therapies & services

- ▶ Early intervention for children with ASD: getting started
- ▶ Autism spectrum disorder (ASD): overview of the services environment
- ▶ Choosing ASD interventions
- ▶ Types of interventions for children with ASD
- ▶ ASD interventions: how they're tested

Basics about ASD

- ▶ Autism spectrum disorder (ASD)
- ▶ Autism spectrum disorder: early signs
- ▶ Autism spectrum disorder (ASD): causes
- ▶ Worried your child has autism spectrum disorder (ASD): what to do
- ▶ Autism spectrum disorder (ASD): how it is diagnosed

Your feedback

This section is a work in progress. Share your **feedback** to help us make it the resource you need.

My neighbourhood

Look up autism services, doctors, pharmacies and speech pathologists on a local **interactive map**.

Helping Children with Autism

Funded by Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.



Early Days

www.earlydays.net.au

1800 334 155







Our Journey to Diagnosis



Timeline of Diagnosis

- **Born 1 May 2004**
- **Started at Child Care 2005 – 13 months**
- **3 years old noticing different behaviours**
 - **3 year old hearing test**
 - **Referral through child care to speech and O.T**
 - **Group sessions started in child care room**
 - **Referral from Paediatrician to Psychiatrist, 9 month waiting for Assessment and Diagnosis**
- **Ralph diagnosed with highly functional Autism**









SNAICC/ PRC Early Days Project Presentation to the SNAICC Conference 2010

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PROJECT OBJECTIVES

1. To ensure Early Days workshops are inclusive and welcoming of Aboriginal and Torres Strait Islander families
2. To help services and organisations working with Aboriginal and Torres Strait Islander 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 meeting the needs of Aboriginal and Torres Strait Islander families with a child with ASD





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SNAICC's broader policies support the current research

- Support families to care for children
- Thrive by five with Culture Alive

Guiding Principles for the project

- Listening to the views of Aboriginal and Torres Strait Islander people
- Providing something back to Aboriginal and Torres Strait Islander families and communities as the project progresses





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EARLY DAYS PROJECT ON AUSTISM SPECTRUM DISORDERS OVERVIEW OF SNAICC/PRC PROJECT

Main elements of the project:

- (1) Early Days Training for Aboriginal and Torres Strait Islander child care staff
- (2) Interviews with for Aboriginal and Torres Strait Islander parents
- (3) Interviews with Aboriginal and Torres Strait Islander service providers





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AUTISM SPECTRUM DISORDERS

SNAICC/PRC PROJECT

Full report available end August 2010

SNAICC website: www.sniacc.asn.au

- Resource Service
- Projects
- Early Days





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Aboriginal and Torres Strait Islander Child Care Centre Workshops

- Workshops conducted by SNAICC and PRC reached over 20 Aboriginal and Torres Strait Islander child care centres in WA, Qld, NT, NSW, SA and Vic
- Why run workshops in Aboriginal and Torres Strait Islander child care centres ?







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INTERVIEWS WITH FAMILIES

Awareness of autism in Aboriginal and Torres Strait Islander communities is low

"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."

"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."





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Attitudes towards Autism in Aboriginal families and communities

“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.”

“The kids call out to him in town – and it makes my other kids know that he’s accepted.”

“This is how he is – we love him for how he is.”





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Challenges

“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.”





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Paths to diagnosis

Some experienced difficulties getting a diagnosis

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

"We knew something was wrong – it's just getting the right people to listen."

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





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Feelings after diagnosis

“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.”

“After diagnosis I felt: ‘It’s over now- now we can get him help’, but later I felt guilty because I hadn’t done anything earlier.”





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Family and Community Issues

Extended family caring for children with ASD

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

"The strongest thing about Aboriginals is our support system. I don't think we'd be able to cope without it."

"I want my 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."





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Culture and ASD

Families value bringing up their children 'strong in culture'





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Racism and ASDs

- Worry that their children's behaviour might result in 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."

"A European child with autism would be accepted more than what a little Aboriginal child would be."





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INTERVIEWS WITH AGENCIES

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 families pace otherwise we might lose them” Slow walk besides the family to achieve the same goals.”*
- 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’.”*





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How to be more sensitive to cultural issues

- Invitations to attend information sessions or assessments should be extended to anyone in the extended family or community that the parents want to invite.
- Shame and lack of understanding about the causes of Autism may be issues for some families. *“I’ve done something wrong leads to reluctance to do something about it”*
- Resistance to labelling may be an issue for some families. *“Its 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”*





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- Recognise genuine fear of protective services getting involved.
- 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”





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How to support Aboriginal and Torres Strait Islander families with a child with autism- a summary

- Focus on building good relationships.
- Provide services within Aboriginal and Torres Strait Islander services e.g. Multi-functional Aboriginal Children's Services
- Provide cost free services
- Do not assume that families can afford to pay upfront and then be reimbursed later





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- Deliver information or services at trusted Aboriginal or Torres Strait Islander agencies and trusted Aboriginal or Torres Strait Islander venues.
- Use trusted Aboriginal or Torres Strait Islander facilitators.





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