What is important to Aboriginal and Torres Strait Islander families raising Autistic children?

This study explores the experiences of Aboriginal and Torres Strait Islander women raising and supporting Autistic children. It explores getting a diagnosis, finding services, providing daily care, keeping children safe, and receiving support that respects culture, family, and the strengths of Autistic children.

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Audience: Families and carers; Service providers
Priority cohort: Children and young people; First Nations People; Women and girls
Context: Health and support services; Home and family
Location: Australia; Metropolitan; Regional; Rural

Read the current online version at:
https://autismhub.com.au/knowledge-library/what-is-important-to-aboriginal-and-torres-strait-islander-families-raising-autistic-children/

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At a glance

Who may find this snapshot useful and why?

This snapshot may help Aboriginal and Torres Strait Islander families learn about the experiences shared by other Aboriginal and Torres Strait Islander families in research. This snapshot shares what women in the study said about raising Autistic children. So, it may help health workers, educators and support services understand families' experiences. It may help them to understand how to work with families in ways that respect their culture, knowledge, and choices.

What is this study about?

Earlier studies about mothers raising Autistic children mostly included White, middle-class women. Less is known about the experiences of Aboriginal and Torres Strait Islander women. The researchers wanted to understand what this support work was like in different communities and why culturally safe services matter.

Why did we choose to create a snapshot of this study?

Aboriginal and Torres Strait Islander families may already know about the challenges of finding support that respects their culture and understands their children's needs. We wanted to share this study because there is little research on this topic. This study brings together women's experiences and shows why it matters to listen to families, respect their knowledge, and provide support that families experience as culturally safe.

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What are the key takeaways from this research?

1 Getting a diagnosis and finding services could be difficult

- Women described how getting an autism diagnosis could be hard, costly, and slow. Some families travelled far or waited a long time.
- Finding services that respected culture, family, and Country was especially important. However, this support was not always available.

2 Helping children take part in everyday life

- Women described supporting their children with everyday tasks, including communication, eating, and daily routines.
- Women taught their children skills and learned more about autism to support them.

3 Keeping children safe and respected

- Women spoke about bullying at school, stigma in public, and unfair treatment in health care. They wanted their children to be safe and treated with respect. Women described protecting their children from these things.
- The women wanted others to recognise and respect their children's individual needs, feelings, and choices.

4 Family, culture and strengths were important

- Women were proud of their children’s strengths, talents, and interests.
- They described the importance of children knowing they belonged within their families and communities.
- Family, cousins, grandparents, and community helped children feel loved and included.
- Some women helped other families by sharing information and starting support groups.

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What can I do with this information?

These are some ways you could use what the researchers learned. The researchers did not test whether these suggestions work.

For Aboriginal and Torres Strait Islander families

- Ask services what they do to make sure Aboriginal and Torres Strait Islander families feel welcome, respected, and safe.
- Ask whether Aboriginal and Torres Strait Islander staff or support workers are available, if this is something you would prefer.
- Choose whether to include grandparents, other family members, or trusted people in meetings and decisions about your child's support.
- Ask services what help is available with appointments, travel, costs, or finding other services.

For people providing autism or family support

- Ask what matters to the child and family, what support they want, and what has or hasn't worked for them before.
- Ask who the family would like involved in meetings and decisions. Do not assume all families have the same needs or preferences.
- Give clear information about assessments, costs, and waiting times. Offer to help arrange appointments or contact other services, if the family would like this.
- Ask about each child's interests, abilities, and connections with family and community. Include these when planning support.
- Take concerns about racism, bullying, or disability discrimination seriously. Ask families what action they would like you to take and follow up with them.

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For services working with Aboriginal and Torres Strait Islander families

- Involve Aboriginal and Torres Strait Islander people in planning, running, and reviewing of services. Make sure they have a say in decisions, not just opportunities to give feedback.
- Review costs, waiting times, travel needs, and appointment options. Consider sending staff to visit families or offering online appointments where suitable.
- Work with Aboriginal and Torres Strait Islander staff and communities to review whether services respect families' cultures, knowledge, and choices.
- Make it clear how families can raise concerns, including who they can speak to and what will happen next. Make sure concerns are taken seriously and acted on.
- Ask families what is working and what needs to change. Explain how their feedback has been used to improve the service.

Questions to think about based on this study

If you are a parent, carer or family member

What support would best respect our culture, family, language, Country and our child's strengths?

If you provide autism or family support

How can I listen better, respect the family's knowledge and make support easier?

If you work in a service

What can our service change to make support more culturally safe, welcoming and easier for families to use?

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One thing to remember

Families may need more than a diagnosis and services. They also need support that respects culture, family relationships, children's strengths and the communities they belong to.

Looking more closely at the study

Why and how was the study done?

The researchers wanted to understand the experiences of Aboriginal and Torres Strait Islander women raising Autistic children. Few studies had asked these women to share their experiences. The study explored how women supported their children, what mattered to their families, and the challenges they faced when accessing services and support.

This was an interview study. Researchers spoke with people to learn about their experiences, thoughts, and views in detail. Each woman took part in an interview in a place or format that suited her. Some interviews were in person, while others were by phone or video. Aboriginal advocates supported some women.

Who was involved?

- 12 women took part. There were 11 mothers and one grandmother, aged 30-63 years.
- Together, they supported 16 Autistic children and young people (15 boys and one girl) aged 2-22 years. Most children and young people had other health, learning, or mental health conditions.

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- The women lived in urban, regional, and remote areas across Australia, including the Torres Strait Islands.
- The women identified as Aboriginal, South Sea Islander and Native American, and Torres Strait Islander.

Who helped shape the research?

The research was shaped with input from the Autistic and autism community, and First Nations communities. This included:

- Collaboration with disability, autism, and First Nations organisations
- Community input on documents provided to families

The research team included two mothers of Autistic children, one who was Aboriginal.

What are some questions that are still unanswered?

This study is useful for understanding the experiences of a small group of Aboriginal and Torres Strait Islander parents, but there are more questions to ask to improve support for this group.

- The study explored Aboriginal and Torres Strait Islander women's experiences of supporting their Autistic children but did not include the perspectives of Autistic people themselves. What services would Aboriginal and Torres Strait Islander Autistic people themselves want?
- Women described the importance of culturally safe services and experiences where services did not understand Aboriginal and Torres Strait Islander cultures. How can autism services become more culturally safe in different communities?
- Families in remote and regional communities faced barriers to getting support. What changes could make diagnosis and support easier to access in these communities?

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One study rarely changes practice.

When making decisions, it is important to consider this study alongside:

- People's values, needs, and lived experience
- Findings from other research studies
- Professional knowledge and expertise

All of these are important parts of an evidence-based approach.

Citation

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