

Perinatal experiences of Autistic people

This report provides an overview of a research study conducted by the Aspect Research Centre for Autism Practice (ARCAP), in partnership with external collaborators. We explored the pregnancy and early parenthood experiences of Autistic individuals in Australia, addressing the unique healthcare barriers they may face.

Working in partnership

Our research team included Autistic people and healthcare professionals whose insights have shaped every aspect of this work, helping us to ensure it is relevant, respectful and practical. We would like to thank all of the research participants and healthcare professionals who shared their stories with us. It is through their generosity and authenticity that we have been able to create a suite of resources that truly reflect the real-world needs, challenges and strengths of Autistic people navigating the healthcare system during pregnancy and early parenthood.

Project team

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Background

Autistic people often face significant challenges in navigating healthcare systems, particularly during the vulnerable perinatal period. Many report inadequate care, feeling misunderstood and unsupported in addressing their health needs.

What we did

We explored the pregnancy and early parenthood experiences of Autistic individuals in Australia, focusing on the unique healthcare barriers they may face. To address this, we interviewed 19 Autistic participants about their pregnancy and early parenthood experiences. A second study sought insights from 12 health professionals. We conducted interviews using multiple modes including written responses, virtual meetings, or phone calls to ensure accessibility. We analysed the data using reflexive thematic analysis. Based on this data and guidance from the advisory team, we developed the Aspect Autistic Pregnancy and Parenthood Hub, a first-of-its-kind online resource for expectant and new parents and the healthcare professionals who support them.



We worked in partnership with a team of Autistic and non-Autistic researchers, practitioners and advisors to design the project



and then listened to stories and experiences from:

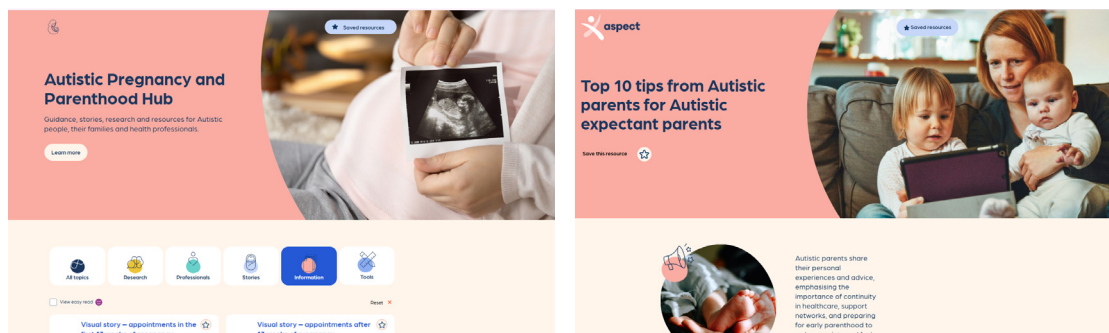
- 19 Autistic participants
- 8 Autistic participants who engaged in an asynchronous Facebook group
- 1 parent on behalf of their Autistic child's pregnancy experiences
- 13 healthcare professionals



to explore how to provide better healthcare experiences and support for Autistic people in pregnancy and early parenthood







and create a digital hub of resources for Autistic people and practitioners.



What we found

Interviews with Autistic participants revealed four themes:

Description	Example quotes
 Theme 1: "Pregnancy was good for me" Participants reflected feelings of body positivity and empowerment during pregnancy.	"I quite like being pregnant, the idea of having this other little being with you all the time. I don't get concerned about body image, it's a cool shape to be! It's nice knowing that even when you don't achieve much else on a given day you're doing something for someone." <i>Avery</i>
 Theme 2: "Hyperfocus is an understatement" Participants expressed intense desire to gather information on every aspect of pregnancy and parenthood, which both facilitated and hindered their wellbeing.	"Like I said, I really like to know the whys and ins and outs of things, makes me feel more sort of supported and in control ... knowledge was really important for me, and feeling comfortable and supported to be able to get that knowledge. That was really important for me." <i>Quinn</i>
 Theme 3: "Lost in the system" Participants described the social drain caused by unpredictable healthcare interactions.	"I hated going to midwife appointments. I never saw the same midwife twice; there was a different one each time. I would be so anxious not knowing who I was going to see." <i>Bailey</i>
 Theme 4: "Making things work for me" Participants detailed the coping mechanisms and strategies they used to manage the demands of pregnancy and early parenthood.	"We also had stuff in the birth plans that was all about me anticipating what my sensory and social needs would be in a difficult situation. In retrospect very tied up with autism but not known at the time." <i>Avery</i>

From professionals, we learned two key themes:


- 1 How care should be adapted for Autistic people during pregnancy and parenthood
- 2 How to move beyond accommodations towards autism acceptance in healthcare. Barriers were discussed including a lack of training, restrictive policy, and wider systematic challenges including safety around disclosure for Autistic professionals.

Many professionals reported having "zero training on autism, neurodivergency, ADHD, all of it," leaving them uncertain about how to address these topics with patients or provide individualised care to Autistic people.

"And I tried to leave written resources and things like that that she could go back to later ... So hopefully when she got a bit more sleep, that sort of helped a bit."

Introducing the Aspect Autistic Pregnancy and Parenthood Hub


Based on rich data sourced by our research and guidance from our advisory team, we have developed the Aspect Autistic Pregnancy and Parenthood Hub, a first-of-its-kind online resource for expectant and new parents and healthcare professionals who support them.




Autistic Pregnancy and Parenthood Hub

Guidance, stories, research and resources for Autistic people, their families and health professionals.


Learn more




Saved resources




All topics




Research




Professionals



Stories



Information



Tools





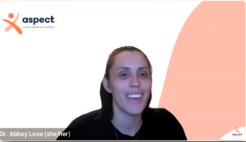
Research summaries in written, video and Easy Read formats

Interactive training modules and tips

Autistic parents share their stories

Resources, tips and visual stories

Visual supports, customisable neuroaffirming plans and checklists



Aspect Autistic Pregnancy and Parenthood Hub
aspect.org.au/new-parents

