



Thriving Together: Co-Creating Well-being Supports for Parents of Autistic Children

Policy Brief

Prepared by: Autism SA

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Supporting Parent Wellbeing to Strengthen Families, Communities and Service Systems

Parents of autistic children play a critical role in supporting their child's development, wellbeing and participation. Yet many experience sustained burnout, social isolation and emotional exhaustion while navigating complex health, education and disability systems. This policy brief presents the findings from the *Thriving Together* project and outlines opportunities to strengthen parent wellbeing through flexible, community-led and preventative approaches.

Acknowledgement

Autism SA gratefully acknowledges the generous support of the **Fay Fuller Foundation** through its Spark Grant Program, which made this project possible.

We sincerely thank the more than **130 parents of autistic children** who generously shared their experiences, challenges and ideas throughout this project. Your openness, honesty and willingness to contribute have created a stronger understanding of the supports parents need to thrive and have shaped the recommendations presented in this brief.

We also acknowledge **Peta Richards**, Project Facilitator, whose dedication to supporting parents and creating safe, welcoming spaces enabled authentic conversations and meaningful co-design throughout the project.

Executive Summary

Parents of autistic children experience significant and ongoing pressures that affect their wellbeing, mental health, social connection and ability to sustain caring responsibilities over time. Through decades of service delivery, community engagement and Autism SA's Information Line, parent wellbeing has consistently emerged as one of the most significant unmet needs within the autism community.

The **Thriving Together: Co-Creating Well-being Supports for Parents of Autistic Children** project was delivered by Autism SA between July 2025 and June 2026 with funding from the Fay Fuller Foundation. The project used a community-led, co-design approach to better understand the wellbeing experiences of parents, identify barriers to accessing support and explore what meaningful, accessible and sustainable parent wellbeing initiatives could look like.

More than **130 parents of autistic children** participated through surveys, focus groups, consultations and co-design activities. The findings revealed that many parents are living in what they described as

"survival mode"—balancing intensive caregiving responsibilities with advocacy, navigating complex systems, financial pressures and emotional fatigue, while having little opportunity to prioritise their own wellbeing.

The project identified several key factors affecting parent wellbeing:

- **73.7%** reported burnout, stress and anxiety.
- **68.4%** identified navigating services and systems as a major challenge.
- **60.5%** reported having little or no time for themselves.
- **47.4%** experienced ongoing challenges relating to school and education.
- **42.1%** identified a lack of respite or childcare.
- **39.5%** reported financial pressures.
- **36.8%** experienced isolation and loneliness.

Parents consistently identified that current systems remain largely focused on supporting the autistic child, while the wellbeing of parents and caregivers is often overlooked despite being fundamental to family resilience, stability and long-term outcomes.

The project also found strong support for flexible, community-based approaches that combine peer connection, practical guidance, lived experience and opportunities for parents to focus on their own wellbeing.

The findings demonstrate a clear opportunity to strengthen autism policy and service delivery by recognising parent wellbeing as an essential component of supporting autistic children and their families.

Why This Matters

Parents of autistic children provide substantial unpaid care that underpins Australia's disability, education, health and community systems. Beyond their role as caregivers, many also become advocates, coordinators, educators, therapists and navigators of complex service systems. While these responsibilities are critical to supporting their children, they often come at considerable personal cost.

The *Thriving Together* project found that many parents experience sustained stress, emotional exhaustion and social isolation while attempting to coordinate services, advocate within education and employment systems, manage financial pressures and balance the competing demands of family life. For many, opportunities to prioritise their own wellbeing are limited or non-existent.

These challenges extend beyond individual families. When parents experience prolonged burnout or declining mental health, the impacts can be felt across multiple systems, including increased demand for health services, crisis supports, education services and disability providers. Supporting parent wellbeing is therefore not only an investment in individual families, but also in stronger communities and more sustainable service systems.

The findings highlight the importance of shifting from crisis-driven responses towards earlier, preventative approaches that build resilience, strengthen peer connections and provide practical support before families reach breaking point.

Importantly, parents did not ask for more complex programs or additional clinical services. They asked for opportunities to connect with others who understand their experiences, practical assistance navigating everyday challenges and flexible supports that recognise the realities of family life.

Investing in parent wellbeing is an investment in healthier families, improved outcomes for autistic children and stronger, more connected communities. The evidence from this project demonstrates that relatively simple, community-led approaches have the potential to make a meaningful difference to families while contributing to more sustainable disability, health and education systems.

About the Project

The **Thriving Together: Co-Creating Well-being Supports for Parents of Autistic Children** project was delivered by Autism SA between July 2025 and June 2026 with funding from the Fay Fuller Foundation Spark Grant.

The project responded to a significant gap consistently identified by parents, Autism SA's Information Line, service delivery teams and community engagement activities: while considerable attention is given to supporting autistic children, far less focus is placed on the wellbeing of the parents and caregivers who support them every day.

Using a community-led, co-design approach, the project sought to better understand the experiences of parents of autistic children, identify barriers to accessing support, and explore what meaningful, practical and sustainable parent wellbeing initiatives could look like.

More than **130 parents of autistic children** participated through surveys, focus groups, consultations and co-design activities. Their lived experiences shaped the findings and informed the development of a draft community-led parent wellbeing support model. The project also trialled elements of this model to better understand how flexible, peer-led approaches could support parent wellbeing in practice.

The project was guided by four key objectives:

- Understand the factors influencing parent wellbeing.
- Identify barriers preventing parents from accessing support.
- Explore the types of supports parents value most.
- Develop practical recommendations to inform future policy, funding and service delivery.

Key Findings

The project identified a clear and consistent message: **parents of autistic children are experiencing significant and sustained pressure, while existing systems often fail to adequately support their own wellbeing.**

1. Parent wellbeing is under significant strain

Many parents described living in "survival mode", balancing intensive caregiving responsibilities alongside advocacy, employment, family responsibilities and navigating complex service systems.

The most commonly reported factors affecting wellbeing were:

Challenge	Parents Reporting
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Burnout, stress and anxiety	73.7%
Navigating services and systems	68.4%
Lack of time for themselves	60.5%
School-related challenges	47.4%
Lack of respite or childcare	42.1%
Financial pressures	39.5%
Isolation and loneliness	36.8%

Across all engagement activities, parents described ongoing emotional fatigue, limited opportunities to prioritise their own wellbeing and the cumulative impact of continuously coordinating supports for their children.

Parents consistently described feeling emotionally exhausted and overwhelmed.

“Exhaustion makes it hard to make good health choices such as exercise and eating well.”

2. Existing supports often do not reflect the realities of family life

Parents reported that many current supports:

- require rigid attendance
- are delivered at unsuitable times
- involve lengthy waiting periods
- focus primarily on the autistic child
- create additional pressure rather than reducing it
- are difficult to access alongside caregiving responsibilities.

Rather than requesting more services, parents consistently identified a need for supports that are practical, flexible and responsive to the realities of everyday family life.

One parent explained:

“Support needs to reduce pressure, not become another thing to manage.”

3. Peer connection is a protective factor

One of the strongest findings was the importance of connecting with other parents who genuinely understand the experience of raising an autistic child.

Parents described peer connection as helping to:

- reduce isolation

- improve emotional wellbeing
- build confidence
- share practical strategies
- create a sense of belonging
- strengthen resilience.

Many participants explained that opportunities to connect with other parents were just as valuable as formal information or professional advice.

4. Flexibility determines participation

Parents consistently reported that support is only accessible when it fits around the realities of family life.

The strongest enablers of participation were:

Participation Enabler	Parents Reporting
Flexible session times	71%
Free or low-cost participation	63%
Childcare or supervised children's areas	45%
Small group environments	45%
Online participation options	39%

Parents also highlighted the importance of local venues, familiar environments, easy parking, flexible attendance and opportunities to participate without feeling pressure to commit every week.

5. Parent wellbeing initiatives must be neuro-inclusive

The project also highlighted the importance of recognising that many parents are themselves neurodivergent.

During one focus group, **10 of the 15 participating parents identified as autistic or ADHD**, reinforcing the need for supports that consider sensory preferences, communication styles, flexibility and accessibility.

Supporting parents requires recognising the diversity of experiences within families and ensuring wellbeing initiatives are designed to be inclusive from the outset.

What Parents Told Us

Parents consistently described wanting support that reduced pressure rather than added to it. They were not seeking highly structured programs or additional obligations—they wanted opportunities to

connect, feel understood and receive practical support from people who genuinely understood their experiences.

Several recurring themes emerged throughout the project.

"We're living in survival mode."

Many parents described feeling emotionally and physically exhausted after years of balancing caregiving, advocacy, employment and navigating complex systems.

"We have forgotten what we used to like to do because we have been in survival mode for so long."

"We want people who understand."

Parents repeatedly spoke about the relief that comes from connecting with others who have shared lived experience.

"Most people don't 'get it', even well-meaning friends and family."

"Having the ability to share with a group like this reduces isolation because you're with people who understand the reality without judgement or advice."

"Support should make life easier—not harder."

Parents emphasised that wellbeing supports must reduce burden rather than become another task to manage.

"Support needs to reduce pressure, not become another thing to manage."

Flexibility, practical assistance and welcoming environments were consistently identified as more important than formal or highly structured programs.

Parents want practical, community-led support

Across surveys, consultations and co-design activities, parents consistently prioritised four areas of support:

- **Peer connection** – opportunities to connect with others who understand.
- **Practical guidance** – help navigating education, disability and service systems.
- **Parent wellbeing** – time and space to rest, reconnect and focus on themselves.
- **Learning and skill building** – practical strategies that can be applied in everyday family life.

These findings demonstrate that strengthening parent wellbeing is not simply about providing more services. It is about creating accessible, flexible and community-led opportunities that recognise parents as individuals, build connection and reduce the pressures they experience every day.

Policy Implications

The *Thriving Together* project demonstrates that supporting the wellbeing of parents of autistic children is not separate from supporting autistic children—it is fundamental to achieving positive outcomes for individuals, families and communities.

The findings highlight a clear opportunity for governments, funders, service providers and community organisations to strengthen existing autism and disability supports by recognising parent wellbeing as a core component of family wellbeing.

Recognise Parent Wellbeing as a Policy Priority

Parents play a central role in supporting their children's development, education, health and participation. Despite this, parent wellbeing is rarely recognised as a priority within autism, disability or family support policy.

Recognising parent wellbeing as an essential element of family support would encourage more holistic approaches that strengthen resilience, improve family functioning and promote long-term outcomes for autistic children and their families.

Invest in Preventative and Community-Based Supports

Parents consistently described seeking support only after reaching crisis point because preventative supports were limited or unavailable.

Investing in community-based wellbeing initiatives that provide connection, practical guidance and early support has the potential to reduce burnout, strengthen resilience and lessen future demand on health, disability, education and crisis services.

Design Services Around the Realities of Family Life

Traditional service models often require fixed attendance, lengthy commitments and participation at times that are difficult for parents managing complex family responsibilities.

Future initiatives should prioritise flexibility through local delivery, hybrid participation options, welcoming community environments and opportunities for parents to engage in ways that suit their individual circumstances.

Embed Lived Experience in Service Design

Parents consistently emphasised the importance of supports designed with, rather than for, the people who use them.

Co-design and lived experience leadership should be embedded throughout the planning, implementation and evaluation of future parent wellbeing initiatives to ensure supports remain relevant, practical and responsive to changing community needs.

Recommendations

For Policymakers

- Recognise parent wellbeing as an essential component of autism and disability policy.
- Include parent wellbeing outcomes within future autism strategies, action plans and family support initiatives.

- Promote preventative approaches that strengthen families before they reach crisis.

For Governments and Funders

- Invest in sustainable parent wellbeing initiatives alongside child-focused supports.
- Support long-term, community-based peer connection programs rather than short-term pilot projects.
- Fund flexible models that can respond to the diverse needs of families across metropolitan, regional and rural communities.
- Support ongoing evaluation to strengthen the evidence base for parent wellbeing initiatives.

For Service Providers

- Design supports that reduce burden rather than add to it.
- Offer flexible participation options, including face-to-face, online and drop-in opportunities.
- Incorporate lived experience and peer connection into service delivery.
- Recognise and accommodate the diversity of neurodivergent experiences within families.

For Community Organisations

- Create welcoming, low-pressure environments that foster genuine connection and belonging.
- Facilitate practical learning opportunities alongside peer support.
- Build partnerships that strengthen local referral pathways and community networks.
- Continue to co-design programs with parents to ensure supports remain relevant and responsive.

Conclusion

The *Thriving Together* project provides compelling evidence that the wellbeing of parents of autistic children remains a significant and often overlooked area of need.

Parents described lives characterised by ongoing advocacy, complex system navigation, emotional exhaustion and limited opportunities to prioritise their own wellbeing. Despite these challenges, they also shared a clear vision for what meaningful support looks like: opportunities to connect with others who understand, practical guidance to navigate everyday challenges and flexible supports that recognise the realities of family life.

The project demonstrates that strengthening parent wellbeing does not necessarily require complex or highly clinical interventions. Community-led, peer-informed and preventative approaches have the potential to reduce isolation, build resilience and improve wellbeing while strengthening families and communities.



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Investing in parent wellbeing is an investment in healthier families, improved outcomes for autistic children and more sustainable disability, health and education systems.

As one parent reflected:

"Feeling less alone makes me more resilient, and that flows directly to my child's wellbeing."

The voices of more than 130 parents involved in this project provide a clear message: supporting parents is not an optional addition to autism services—it is fundamental to creating stronger families, thriving communities and more inclusive systems.

Enquiries

For further information about the **Thriving Together: Co-Creating Well-being Supports for Parents of Autistic Children** project, or to discuss opportunities to partner with Autism SA in strengthening parent wellbeing initiatives, please contact:

Autism SA

Research, Projects and Resources

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Autism SA welcomes opportunities to work collaboratively with governments, funders, researchers, service providers and community organisations to strengthen the wellbeing of parents, families and the broader autistic community.

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This project was funded through the **Fay Fuller Foundation Spark Grant Program**. Autism SA sincerely thanks the Foundation for supporting this important work and the parents who generously shared their experiences to help shape future supports for families of autistic children.

I think this gives you a complete policy brief that is distinct from the full report. The report provides the evidence and detailed methodology, while the policy brief distils the most important findings into a concise document that policymakers and funders can read in 10–15 minutes. It keeps the focus on the case for change and the actions needed, rather than documenting every aspect of the project.