What helps Autistic children live a “good life”?

This study explores Autistic adults’ and parents’ views about what supports Autistic children’s wellbeing. Autistic adults and parents talk about the importance of acceptance, enjoyable activities, choice and control, and physical and sensory environments that meet each child’s needs.

This research paper was written by Kate Simpson, Connie Allen, Elizabeth Wheeley, Elizabeth Pellicano, Melanie Heyworth, Jacquiline den Houting, Rachael Bowen, and Dawn Adams, and first published in 2026.

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Priority cohort: Children and young people
Context: Community and social participation; Health and support services; Home and family; School
Location: Australia

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At a glance

Who may find this snapshot useful and why?

This snapshot may help Autistic children and families explain what matters to them and what support they may need to live a good life. It may also help teachers, health professionals, and support services understand the importance of acceptance, personal interests, choice, and comfortable environments. They could use these ideas to think about how they support Autistic children.

What is this study about?

Research has often used ideas about a good life that may not reflect what matters to Autistic people. This is important, because a good life can mean different things to different people. In this study, Autistic adults and parents of Autistic children shared their experiences and views about what is important in Autistic children's everyday lives. The researchers wanted to understand what helps Autistic children live a good life and what makes life harder.

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

Autistic people and families may already have valuable knowledge and experiences about what helps Autistic children live a good life. We felt this study was important to share because it brings together the views of Autistic adults and parents of Autistic children. It shows that both groups value many of the same things, including acceptance, choice, and opportunities to enjoy life. This may help families, schools, and services think more broadly about what matters for the wellbeing of Autistic children.

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What are the key takeaways from this research?

1 Being accepted for who you are matters

- Autistic children need to feel loved, understood, and respected. They need to have this without pressure to hide their differences or act like someone else.
- For Autistic children, feeling accepted could also mean making friends and connecting with people in their own ways. This might include sharing an interest or enjoying time together without talking much.

2 Children need time for things they enjoy

- Enjoyable activities are a source of joy, energy, and success for Autistic children. These activities can also help Autistic children rest and recharge.
- What an Autistic child enjoys may be different from what other people expect. They may need time to explore their interests and find activities that feel right for them.

3 Autistic children need a say in their own lives

- Autistic children should have choices that suit their age and needs, and adults should respect those choices.
- Children may need different ways to share their choices.
- Choices might include what to wear, eat, or learn; how to spend time; and whether to say no about something.

4 The environment can make a big difference

- Noise, crowds, bright lights, strong smells, uncomfortable temperatures, or lots of change can make some Autistic children feel anxious or overwhelmed.

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- A quieter place to rest, a comfortable space, or planning ahead may help an Autistic child feel safe and join in.

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 Autistic children and young people

- Ask for time to enjoy your interests, even if other people do not understand why you like them. Spend time on your interests and with people who value and accept you. You do not have to enjoy the same things as other people or change who you are to fit in.
- Tell someone you trust about things that make you uncomfortable, such as loud noises, bright lights, or crowded places. You could ask for changes that might help.
- Share your choices in a way that works for you. This might include speaking, writing, drawing, using pictures, or using a communication device.

For families

- Ask your child what they enjoy and what makes them feel happy or comfortable. Notice which activities they choose to do in their free time.
- Make time for your child's interests, even if they are different from what other children enjoy.
- Give your child choices about everyday activities, such as what to wear, what to eat, or how to spend their free time. Make sure they have ways to show their choices.

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- Ask your child what makes places feel comfortable or uncomfortable. You could try changes such as softer lighting, less noise, or different furnishings.
- Respect your child's choices about physical contact. For example, let them choose whether they want to hug someone or say hello in another way.

For educators

- Ask students what they enjoy and find ways to include their interests in learning. For example, students could choose a topic they are interested in for a writing task or project.
- Let students choose how they complete or share their work. They could write, type, draw, or use a communication device.
- Ask students about noise, lighting, and other things that affect their comfort. Consider changes such as reducing background noise, offering headphones, or providing a quiet space.
- Recognise that students communicate and take part in activities in different ways. Ask students what works best for them and offer choices, such as working independently, with a partner, or working in a small group.
- Check whether classroom activities and supports are working for each student. Ask what they would like to change and use their feedback when planning lessons.

For people who design or provide support for Autistic children

- Work with children and families to choose goals that matter to the child. A sample goal could be joining an activity they enjoy or building friendships in ways that feel comfortable to them.

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- Recognise that Autistic students may communicate, make friends, and take part in activities in different ways. Ask students how they prefer to take part and offer choices, such as working alone, with a partner or in a small group.
- Ask children and families about noise, lighting, waiting areas, and other things that may make using a service difficult. Make changes where possible.
- Ask children and families whether the support is helping with things that matter to them. Use their feedback to make changes.

Questions to think about based on this study

If you are an Autistic child or young person

What helps me feel comfortable, included, and able to tell people my choices?

If you are a parent, family member or supporter

What does a good day look like for my child, and how can I support more of these experiences?

If you support Autistic children at school

Does this student feel accepted at school, and how could I better support their interests, communication and preferences?

If you design or provide supports for Autistic children

How can I include Autistic people in the design and review of support, and how will I know whether they are helping people enjoy their lives and achieve what matters to them?

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One thing to remember

A good life does not look the same for every Autistic child. Ask each Autistic child what matters to them. Help them feel accepted, make choices, enjoy things they love and be themselves.

Looking more closely at the study

Why and how was the study done?

There was limited research about what helps Autistic children live a good life. The researchers wanted to understand what matters to Autistic children by bringing together the views of Autistic adults and parents of Autistic children. They hoped this would help families, schools and services better understand what can support Autistic children's happiness, choices and wellbeing. They did not interview Autistic children themselves.

This was an online interview study. Researchers spoke with people to learn about their experiences, thoughts, and views in detail. Autistic adults and parents of Autistic children described their experiences in their own words.

Who was involved?

- 57 people from Australia took part: 28 Autistic adults and 29 parents of Autistic children. Some people who took part were both Autistic and parents.
- The Autistic adults were aged 18–65 years. The parents were aged 29–64 years.
- Most people described themselves as White and female.

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- The parents described the experiences of 29 Autistic children aged 3–20 years.
- All Autistic adults used speech as their main way of communicating and reported no intellectual disability.
- Over half the Autistic adults and nearly 40% of Autistic children had at least one other health or learning condition

Who helped shape the research?

- Academic and community partners were involved throughout the project.
- Community partners included representatives from Autistic-led and other community organisations.
- The academic and community partners helped with the grant application, study design, data collection, data analysis, manuscript preparation, and review.
- Monthly meetings included academic and community team members.
- An Autistic and parent advisory group helped shape the interview wording. They recommended using the phrase “live a good life” because it was more accessible to the community.

What are some questions that are still unanswered?

The study provides findings, but the evidence base remains limited. Some further questions include:

- Parents described their children’s experiences. Autistic adults thought back to their own childhoods. What do Autistic children and young people themselves say makes a good life?

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- The researchers did not compare what mattered to children of different ages or with different support needs. Do different things matter to children with different communication, cultural, gender or support needs?
- The study identified things that may help Autistic children live a good life. How can services use this information to understand what matters to each Autistic child?
- Having choice and control was identified as important. What can make it easier for Autistic children to have a say in their lives, make choices, connect with others, and take part in activities they enjoy?

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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