

RESEARCH PRIORITIES & AGENDA

**What matters to Autistic people,
so they can lead a good life?**



By Dr Trevor Clark, Prof Liz Pellicano, Kaaren Haas, Vicki Gibbs, Ainslie Robinson
Dr Mustafa Al Ansari, Dr Heidi Merrington, Emma Gallagher and Thomas Kuzma

2022

Acknowledgements

This landmark study would not have been possible without the participation and support of the Autistic adults and adolescents, parents and Aspect staff. We thank everyone who generously shared their lived experiences, perspectives and aspirations with us. Your voices will help shape ARCAP's future program of research to ensure it is relevant, respectful and positively impacts the lives of people on the autism spectrum.

The authors would like to recognise the guidance and enthusiasm of members of the Research Priorities Advisory Group who steered this study:

Louise Cummins
Belinda Duncombe
Kaaren Haas
Dr Melanie Heyworth
Dr Genevieve Johnsson
Matthew Oastler
Prof Liz Pellicano
Krishna Sadhana
Yogie Wirastra
Dr Trevor Clark

Finally, thank you to the Autistic people who kindly contributed photographs for this report, enabling us to better capture and reflect what matters to Autistic people.

Aspect Research Centre for Autism Practice (ARCAP)

T 1800 ASPECT (1800 277 328)

E research@autismspectrum.org.au

W autismspectrum.org.au/arcap

The ARCAP Research Priorities study was funded by Autism Spectrum Australia (Aspect).



About the Aspect Research Centre for Autism Practice (ARCAP)

The Aspect Research Centre for Autism Practice (ARCAP) is the research arm of Australia's largest autism-specific service provider, Autism Spectrum Australia (Aspect).

The focus of research at ARCAP is to improve the quality of life for Autistic people of all ages in ways that are meaningful for them. A participatory approach to undertaking research at ARCAP means we draw upon the lived experience of Autistic people and their families and carers, as well as the hands-on knowledge of practitioners to shape and inform our research in autism practice. ARCAP continues to be a leader in participatory research, setting the future agenda in autism practice research in partnership with the Autistic and autism communities.

Developing Aspect's research priorities and agenda

The Research Priorities study was co-produced and directly involved participation and input from Autistic people and parents/carers from around Australia.

ARCAP's future research agenda will be aligned to the priorities resulting from this study. Projects that fill gaps in research will be developed that are relevant to Aspect's programs and services (the Aspect Comprehensive Approach) and are financially viable.

Purpose and aims

The research study aimed to align autism practice research at ARCAP with the priorities of Autistic people and their parents/carers so that they may realise their goals and aspirations through the provision of appropriate services, programs and resources.

In order to achieve this aim, we sought to understand:



1

What does a good life mean for Autistic people and for the parents/carers of Autistic people?

2

What might help or hinder Autistic people and parents/carers in achieving a good life?

Working in partnership

partnership

In line with ARCAP's research in partnership approach, the research team included two Autistic researchers who were active in recruitment, data collection and analysis. The ARCAP Research Priorities Advisory Group was also established that included three Autistic adults, three parents of Autistic children, three autism practitioners and three autism researchers to inform all stages of the research process. The research method including key documents such as participant information, survey and interview schedules, were all co-produced with the Autistic researchers and the advisory group.



ARCAP Research Priorities Advisory Group, 2019

Phase One

Phase One of the study involved interviews with Autistic adults (n=34) and adolescents (n=14) and parents/carers of Autistic people of all ages (n=31) from around Australia. This phase aimed to understand what a good life means for Autistic people and parents/carers of Autistic people and what might help or hinder them in achieving this good life.

Recruitment for participation in this research was carried out via social media and via autism service organisations, schools and autism networks. A specific attempt was made to reach marginalised communities and groups from around Australia. The online registration process included a simple English and a high support needs participant information and consent form, including visual cues.

Participants who consented, were provided a choice to participate in a live interview, record an audio or video response or provide their answers in written form. Where a participant chose a live interview, a mutual time was agreed. Where possible, interviews with Autistic participants and their parents/carers were carried out by an Autistic research team member, as advised by the advisory group. Interviewees allowed participants to conduct the interview at their own pace – and allowed for short breaks, if needed.

Following data collection, analysis of the interviews was done in consultation with Autistic research team members as well as the advisory group. Interpretation of the findings was conducted in close participation with Autistic team members and then presented to the advisory Group for comment. A total of 14 key themes were identified based on the information provided by participants in this phase of the study.

Phase Two

During Phase Two of this study, Autistic people accessing Aspect services (n=7), parents/carers of Autistic people accessing Aspect services (n=32) and Aspect staff that work with Autistic people (n=54) completed a brief online survey. The survey presented the 14 key themes derived from Phase One in a clear and visual manner. Participants were asked to categorise each theme according to degree of importance and to identify which three of the 14 themes were of most importance to them. Results from the degree of importance question indicated that all 14 themes were deemed to be of similarly high levels of importance to participants. However, when asked to identify the top 3 topics; most parents (n=18; 56%) chose making and keeping friendships as a top 3 topic, followed by advocacy (n=12; 38%) and parent/family wellbeing (n=12; 38%). Most staff (n=30; 56%) chose mental health as a top 3 topic, followed by advocacy (n=19; 35%); and making and keeping friendships (n=16; 30%).

Following the conclusion of both phases of the study, the 14 key themes identified in Phase One were distilled to form eight priority research areas (see figure on page 5). These priority areas were derived by combining some of the themes that related to similar areas. For example, the research area “relationships” that deals with all social connections was derived from two key themes: “making and maintaining friendships” and “making and maintaining relationships”. Similarly, the research priority area of “self-acceptance and acceptance in the community” was derived from a combination of three themes: “acceptance”, “identity” and “advocacy”.

Research priority areas

priority

Relationships

Establishing and maintaining relationships



Mental health

Taking care of mental health



Acceptance

Self-acceptance and acceptance in the community



Workplace

Thriving in the workplace



Education

Enhancing educational experiences



Support services

Accessing autism-specific support services



Adult life and the future

Transition to adult life and outlook for the future



Self-care

Managing self-care and experiencing burnout



Relationships

Establishing and maintaining relationships

Social relationships were a priority for study participants. For some adults, relationships with spouses or partners were not only a source of companionship but also provided practical day-to-day support in challenging areas of their lives and acted as a “bridge” between them and the “neurotypical world”.

However, Autistic participants reported that social differences had resulted in misunderstandings in social situations, which affected their ability to make and maintain friends. Autistic people face unique challenges in establishing and maintaining social communication and connection - especially in intimate relationships. Further, participants reported that misunderstanding the social intent of Autistic people by non-Autistic people may add to the challenge of establishing and maintaining relationships.

How research may help

Further understanding these challenges, as well as the enablers of social connections, may identify ways in which the social needs and preferences of Autistic people can be better supported at various stages in the lifecycle. Research in this area may assist in increased understanding of Autistic people by non-Autistic people as well as in developing programs and supports that may assist in mitigating some of the barriers Autistic people face in social relationships.

“I wish I could spend more time with my friends but I know I drive them nuts so I don’t - that’s an emotional issue because I want the friends but I know if I have too much contact with them they cut me out ... Socially, you want more but you know it’s not going to work unless you’ve got people who really understand, that’s an issue.”

63-year-old Autistic woman

“If I look back on my life, I realise that I’ve predominantly been partnered and it’s usually someone who creates that bridge between my world and the neurotypical world so that I don’t get lost.”

68-year-old Autistic woman

“She [partner] is the only human being in the entire Universe with whom I share my deepest intimacy.”

55-year-old Autistic man

"It's kind of hard to understand what they're feeling and saying and what they like. If people treat me badly or they joke around, I don't know if they're just joking or [if] they are being serious."

14-year-old Autistic boy

"But the other students in school, they most of the time just flat out ignore me. So, I'd like to have a couple more friends, at least in the mainstream classes, but nope. None of them care. Probably because I don't look pretty. I don't act like all the other girls, so they don't want to talk to me, because, oh, I don't want to talk about fashion and TikTok, ugh."

16-year-old Autistic girl



Friendship



Family



Someone to love

Mental health

Taking care of mental health

Almost all of the Autistic adults reported experiencing clinically diagnosed anxiety and depression, with many describing long-term difficulties dating back to childhood. Anxiety and depression were described as being associated with a range of factors including past experiences of trauma and bullying, negative social experiences, unpredictability and change, feelings of low self-worth and the need to 'mask' or pretend to be 'normal' in workplace and social settings. The experience of mental health can be pervasive and result in some Autistic people feeling "a general incompatibility with the world" and wondering if they can "handle the next thing life throws" at them.

Participants shared that they have experienced a lack of appropriate mental health services. Mental health professionals often do not have relevant understanding or knowledge regarding autism and Autistic people.

How research may help

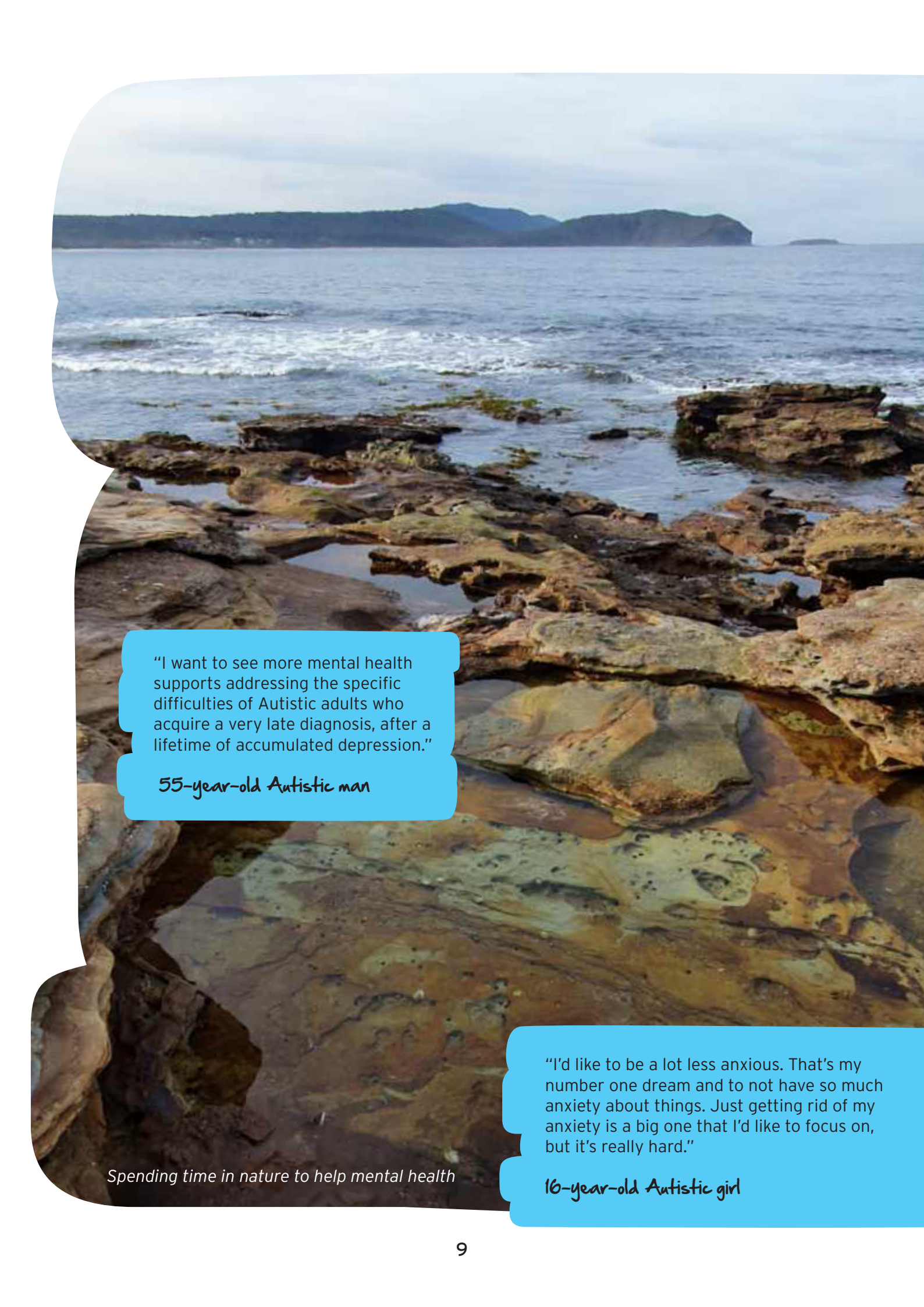
Research into the impact of mental health on Autistic communities and individuals, as well as factors influencing mental health issues among Autistic people, may provide a better understand of the mental health challenges and experiences of Autistic people, and facilitate the provision of appropriate autism-specific and/or autism-friendly services. For example, the capacity of mental health professionals may be built by introducing tailored autism-specific professional development programs. Similarly, online and in-person mental health resources and support may be developed for Autistic people and mental health professionals.

"The way I act is not always socially acceptable, so I started masking. This led to social anxiety and embarrassment for past social mistakes; these haunt me to this day. This constant masking of my Autistic traits, as well as my constant self-gaslighting and the internalised belief that I am a defective human being, has had a devastating impact on my mental health."

18-year-old Autistic man



Ava and Katie



"I want to see more mental health supports addressing the specific difficulties of Autistic adults who acquire a very late diagnosis, after a lifetime of accumulated depression."

55-year-old Autistic man

"I'd like to be a lot less anxious. That's my number one dream and to not have so much anxiety about things. Just getting rid of my anxiety is a big one that I'd like to focus on, but it's really hard."

16-year-old Autistic girl

Spending time in nature to help mental health

Acceptance

Self-acceptance and acceptance in the community

Developing self and community-acceptance was a key priority for Autistic adolescents, adults and parents. Many Autistic people and their families experienced lack of acceptance and social exclusion in their daily lives, including at schools, in workplaces and in social settings. Social stigma and lack of understanding of autism in the community, including in various cultural settings, was also highlighted as a barrier to community acceptance.

Some participants highlighted that self-acceptance and a positive Autistic identity had enhanced their quality of life and that receiving an autism diagnosis could lead to greater self-acceptance.

How research may help

Research exploring factors influencing acceptance of neurodiversity in different settings may inform strategies for enhancing community understanding of autism and building more inclusive and supportive work, school and community environments. Research into the role of Autistic identity, and its influence on self-acceptance and quality of life outcomes for Autistic individuals and their families, may lead to better understandings of how best to provide support.

"It's brilliant knowing that [I'm Autistic]. That's part of feeling really good about my life. I know why I can't do some things and instead of trying to push myself, I just go well yep, that's not the day for doing this and go and do something else good. So, I'm generally happier."

52-year-old Autistic woman

"I don't feel as though I'm treated fairly. I don't feel accepted and included. I feel being the outsider or whatever, the weirdo no-one wants to be around and it's really hard for other people to break that stereotype."

42-year-old Autistic man

"The perception that I have autism in the first place, I think it turns a lot of people off from me. I think that's predominantly a major reason why no-one talked to me in high school. They were like, that sort of stigma that surrounds it."

17-year-old Autistic boy

"Most people don't know [I am Autistic]. Because of the stigma and the [culture] of society and all that kind of thing, I would prefer to keep it that way just for convenience sake."

28-year-old Autistic man



"I would like people with autism to be treated the same as people who don't have it."

14-year-old Autistic boy

"Most of the time, I don't feel like I am in charge of my own life, but I have some say in the things that matter."

16-year-old Autistic boy

Workplace

Thriving in the workplace

Autistic people and their parents/carers viewed employment as an important step in the transition to a more independent adult life. Finding a job that was a “good-fit” and worked to the Autistic person’s strengths was of key importance. A strength-based approach may enhance the experiences of Autistic people in the workplace. Workplaces may also provide more inclusive environments - including by providing tailored and inclusive training and induction programs.

How research may help

Research into how the interests, skills and abilities of Autistic individuals can be best utilised in the workplace, as well as studying how employment programs and workspaces can accommodate Autistic people, may enhance job-seeking experiences and work environments for Autistic adults. Research into programs and supports that improve employers’ understanding of autism may improve the capacity of organisations to employ and appropriately support Autistic people to thrive in the workplace.

“I feel more mistreated than respected. It has cost me many jobs because they want me out because they don’t understand me. I need concise instructions, proper training to do things properly.”

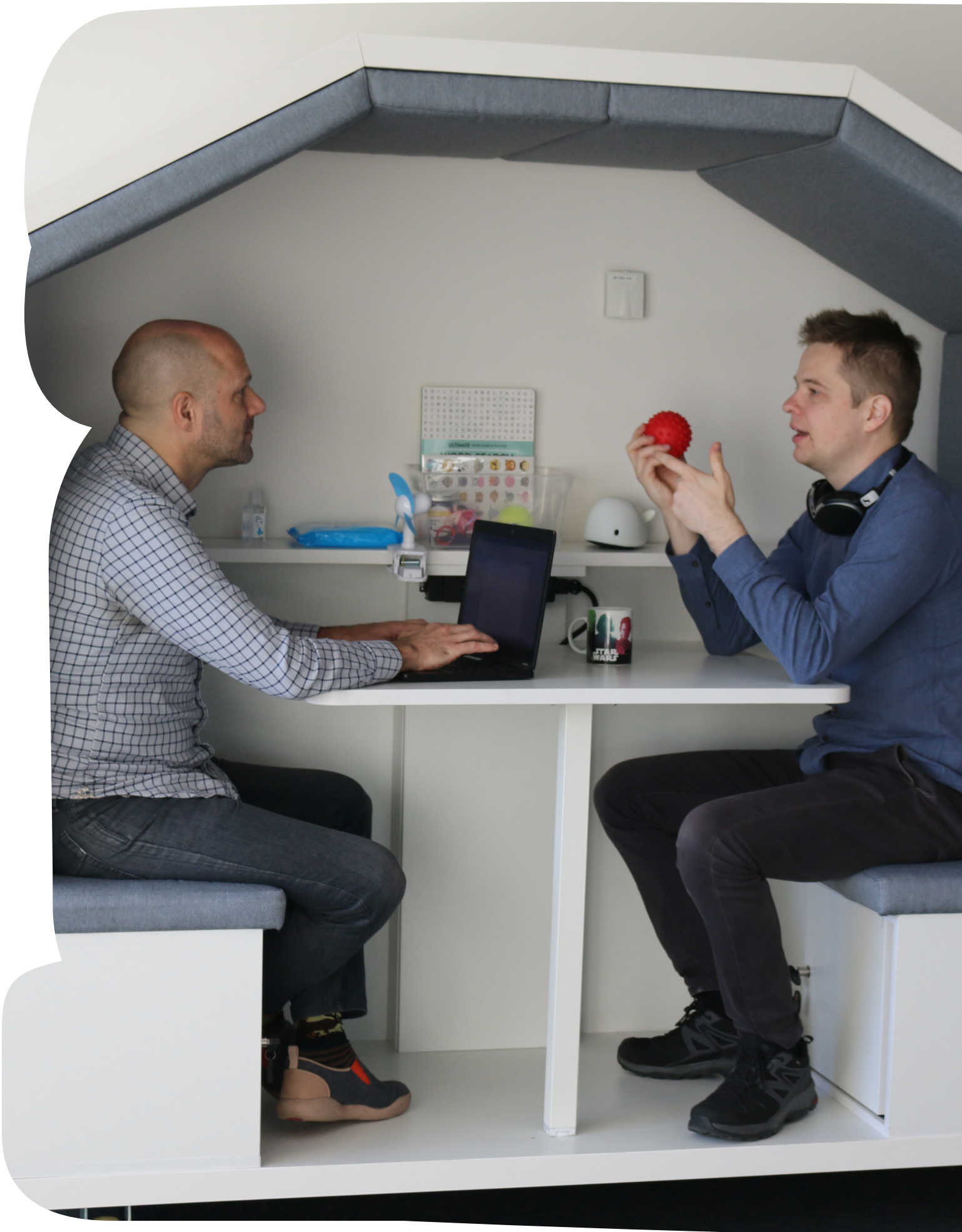
35-year-old Autistic man

“I would like to have a job that I loved and that I can cope with and that’s really stimulating for me and is creative. I would like something that could see me right through.”

46-year-old Autistic woman

“I would like my strengths and my differences to be recognised as strengths. I would like to be recognised for what I really am capable of, what I really do and that my differences contribute to good outcomes for other people. [I]’m good at these things because I’m Autistic - it’s a quiet focussed role and it’s about managing staff. But it makes me really sad that people can’t see that value.”

42-year-old Autistic woman



Education

Enhancing educational experiences

Parents and carers prioritised research aimed at enhancing the educational options and experiences of Autistic children and their families. Lack of implementation of autism-informed teaching practices, accommodations and supports, particularly in mainstream educational settings, had a major impact on children's and parents' quality of life. Improving teacher training and communication with the autism community also enhances student and parent experiences in the educational system.

How research may help

Research focused on how to achieve the best possible educational outcomes for Autistic children would enhance quality of life for children and their families and assist in setting children up for future success. Research that identifies how to provide and tailor effective, autism-informed or specialist education for Autistic children is fundamental to achieving such outcomes. This may mitigate current barriers to implementing evidence-based practices in mainstream schools.

"School tends to be an ongoing challenge. We had a year last year where we had a teacher who was all over it, got it, understood it, worked to his strengths and really made sure that that happened in the classroom. This year we're working with a teacher who, she's a great teacher, but she sees it as behavioural issues, rather than what is it in his setting that's actually triggering him and setting him off, and then if you minimise them, actually the behaviour's not the issue."

Mother of a 7-year-old Autistic child

"He's at [an autism-specialist school]. Brilliant. Just the best thing that's happened to him. They've just got such creative ways of teaching the children and the staff are all so dedicated and interested in knowing as much as they can about each of the children ... We unfortunately didn't have a great experience in early preschool years, so we really appreciate the effort that autism-specialist school is putting into his learning."

Mother of a 7-year-old Autistic child

"The school doesn't deal with him. As soon as he starts they're on the phone to us - can you come and get him - to the extent that he's had massive partial enrolments and we also kept him alone a lot because he was going into fight or flight mode which was making him harder to manage at home"

Carer of an 8 and 11-year-old Autistic child





"I still am very - quite frustrated about some of the language and about some of the education staff views. I think - and potential avenues for discrimination. I've worked really hard to make sure that we're involved, and their education adjustment plans are okay, but there's still a paternalistic attitude that's very [just a focus] that exists within the school system."

*Mother of a 10 and 13-year-old
Autistic child*

Photos: By Lucius Dzam-Robinson who loves the school playground, the feeling of kicking around in woodchips and "One Fish Two Fish Red Fish Blue Fish."

Support services

Accessing autism-specific support services

Access to services, support, financial assistance and government-funded disability packages were priorities for Autistic people and their parents/carers to access the assistance they needed and improve quality of life. Parents prioritised access to respite, therapy services aimed at enhancing their child's skill development, and mental health support for the Autistic person as well as their family, if needed. Autistic adults and adolescents highlighted the need for better access to practical help with managing everyday life, access to medical services and psychological support as particularly important.

How research may help

Research focused on identifying barriers to accessing priority services and how best to offer and deliver services that are acceptable to Autistic people and their families, may make a significant difference to quality of life and well-being. Building the capacity of mainstream health and mental health providers may also be required.

"We're already finding it very difficult to find supports that are suitable for him in a small rural environment. So, to find things that are suitable for a teenager, can only be harder."


Mother of a 9-year-old Autistic child

"Any services we've got we've got by going on the internet. [Autistic child] was diagnosed by a development paediatrician. She gave us an A4 sheet of things, like here's some services you can connect with. Then we never saw her again, but at least on that list there was Aspect, so I think they were the first organisation we connected with. The only things we ever got were if we did the research and then pursued it ourselves."

Carer of an 8 and 11-year-old Autistic child

"I think a lot of services need to understand people with autism and intellectual disability a lot because I don't think they fully understand. Like a few times I called [a crisis support line] and they were just quick to get you off the phone and some of them didn't even know what autism was and things like that and it made me a bit upset actually. It made it worse."

38-year-old Autistic man



"If we could afford more support that would be really good. Even someone just to come in and do the cleaning so that's just one less thing that I have to worry about or to do. Yeah, someone to step in and do some of the things sometimes would be really nice. More support for me. Even just someone to talk to, like someone else who understands."

Mother of a 10-year-old Autistic child

iPads make learning easier when writing is tricky

Adult life and the future

Transition to adult life and outlook for the future

Transition to adult life, independent living and the outlook for the future were identified as key areas of importance to study participants. Uncertainty about the future was highlighted by Autistic adults and adolescents and was a particular concern of parents/carers. Parents/carers wanted their children to be independent but were concerned about limited supports available for adult life, particularly regarding financial security, living arrangement and career - with specific concern about their Autistic child after their parents' deaths.

How research may help

Research into the experiences of Autistic people's transition to adult life may provide better outcomes for Autistic individuals in their experience of transition to living independently.

Research aimed at developing supports for parents and family members of Autistic adults in relation to future planning, would provide much needed reassurance and promote a more positive outlook for the future.

"I don't know. I'm not as optimistic as my husband. I do - I'm very positive about her and I would hope that she'll have a great life, but I still don't know if she'll live independently or if she'd be capable of that. So that's a big worry that weighs on me. That whole - could anyone take care of her the way we do if anything happened to us, and all that sort of thing."

Mother of a 6-year-old Autistic child



My important routine



The safety and comfort of a home you love

"I am hoping for a good job, a loving family (wife and children), a big house"

14-year-old Autistic boy

"I'm worried about next year going into senior as well, meeting some new people, doing new classes and stuff and then I'm even more worried about my life after getting - I'm turning 16 at the end of December. My dad wants me to study the driver's booklet and I keep forgetting and I'm worried about if I get a car I'm going to just crash it and then die in a car crash. I just get - I'm worried about getting a job, like I said I'm worried that I'll stuff up or something. I'm worried about I'm just going to be poor in the future and I'm just going to - nothing good is going to happen to me I'm just going to go down with nothing."

15-year-old Autistic boy

"On some days I feel like my future could be bad, some days I feel like have a bright future."

15-year-old Autistic boy



Navigating the transition to adult life

Self-care

Managing self-care and experiencing burnout

Many Autistic adults described challenges accomplishing daily home, work or other commitments, while maintaining self-care and addressing sensory needs. The need to recharge and maintain a sense of balance was fundamental to maintaining quality of life and for avoiding exhaustion and Autistic burnout.

How research may help

Studying the experiences of Autistic people in managing their daily lives, what supports they may need, as well as how workplaces and living spaces accommodate sensory needs, is important for providing a more acceptable living and work environment for Autistic people.

"I could really do with some practical help. It's not that I can't do it, but my ability to prioritise tasks and multitask and manage my fatigue, I've always been the kind of person who's done everything, I'll just do everything, I can do everything. But I acknowledge that I can't do that anymore and work. So, until I get some practical help, I am paying for some at the moment, but I'm not working, so I'm kind of going, yeah."

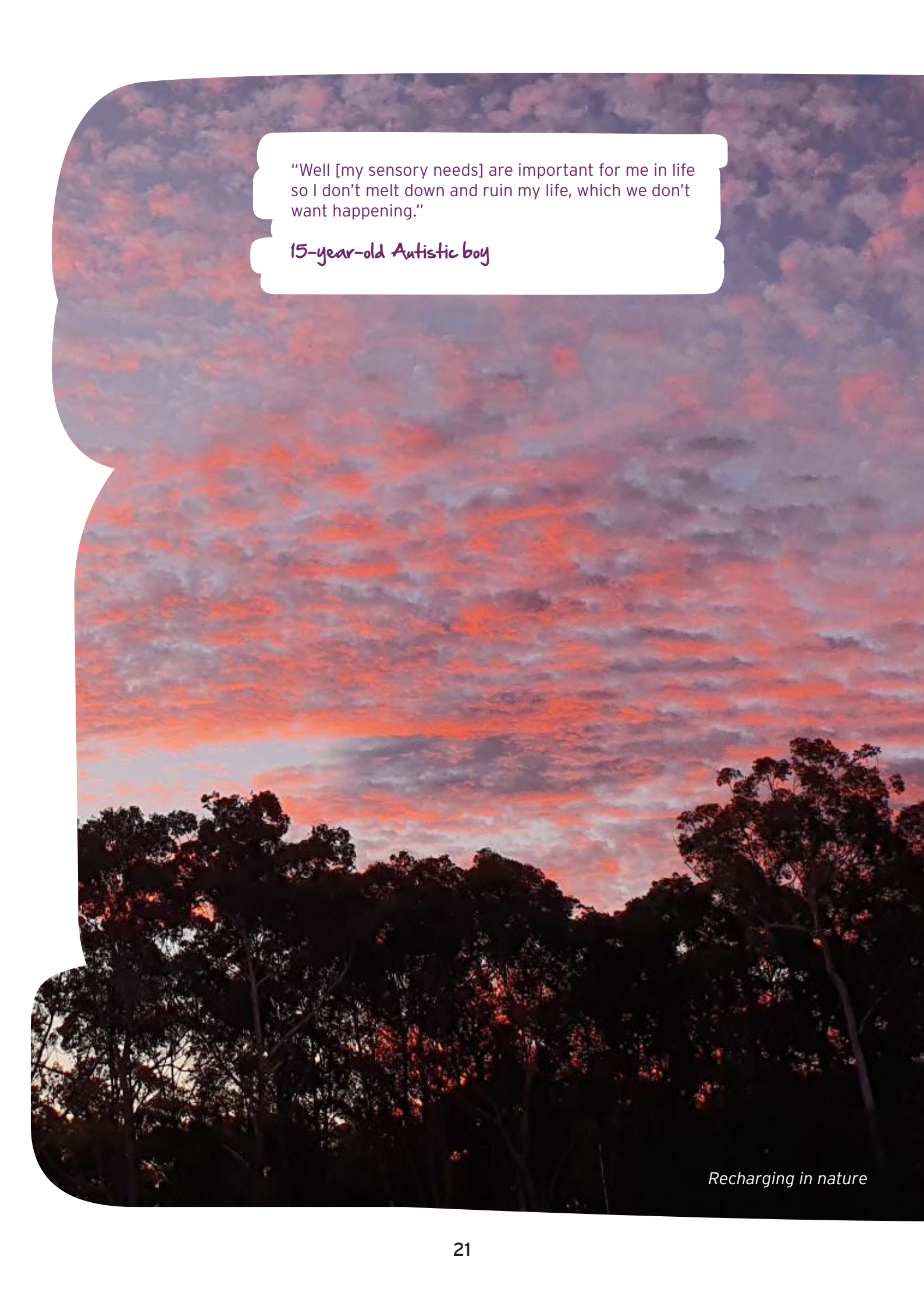
46-year-old Autistic woman

"I find it really difficult, and this might be also because I'm just a single lady or whatever. But there's so much maintenance involved with being a person and I cannot fathom how people are doing this nine-to-five like every day of the week. Then like doing fun or social things on the weekend, and then it's like but where do you get the time to also do the things that you need to do to be a person?"

26-year-old Autistic woman



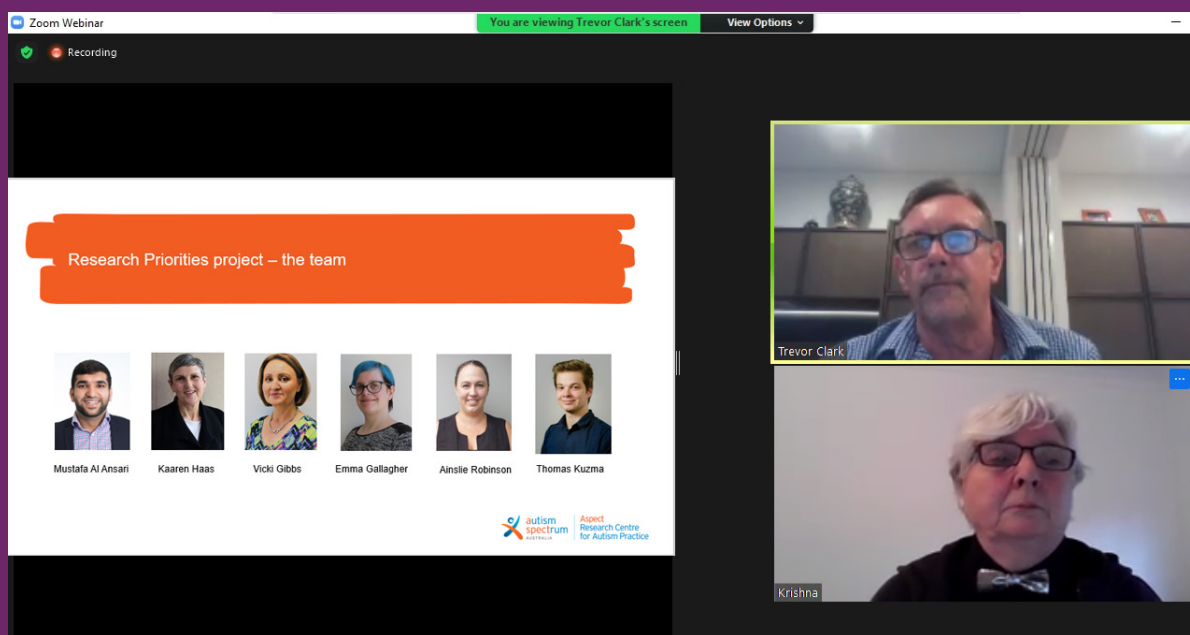
My faith is the centre of my life



“Well [my sensory needs] are important for me in life so I don’t melt down and ruin my life, which we don’t want happening.”

15-year-old Artistic boy

Recharging in nature



Dr Trevor Clark and Krishna Sadhana accepting the Autism CRC Inclusive Research Award, 2021

Concluding remarks



ARCAP is committed to conducting research in partnership with Autistic people and the autism community. This study was co-produced with Autistic researchers and developed in partnership with Autistic people and supported by the Research Priorities Advisory Group. In 2021, the Research Priorities study won the Inclusive Research Category in the Autism CRC Achievement in Autism Spectrum Research Awards.

By working in partnership with Autistic people we now understand their priorities for leading a good life and what is preventing achievement of a good life. Looking to the future, the priorities of Autistic people will not only define the scope of our autism practice research, but will also ensure that our work is respectful and relevant to Autistic people.

Eight priority areas were identified - **Relationships, Mental health, Acceptance, Workplace, Education, Support services, Adult life and the future, and Self-care** - which will underpin ARCAP's research agenda.

The research priorities and agenda will be included in Aspect's strategic and business plans and subsequently inform the continued development of Aspect's research and services. In doing so, we aim to positively impact the lives of Autistic people and support them to realise their goals and aspirations.