

I am Autistic.♥

Disclosure experiences of Autistic adults

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Working in partnership

The studies reflected a “co-produced” model where Autistic and non-Autistic researchers worked together to answer a question of interest that was common to all team members. During the design phase, two Autistic research assistants worked alongside the research team to design the study, review the measures, and offer advice on the methodology. Both research assistants influenced the language that was used in the design of the study, the research questions, and most importantly, the survey items. For study two, an Autistic researcher worked alongside a non-Autistic researcher to carry out the study, and most importantly, to understand and interpret the results.

About this report

This report summarises two ARCAP research studies that examined the disclosure experiences of Autistic adults:

- Study one - *Exploring identity importance for Autistic adults and associations with disclosure experiences*
- Study two - *Using experience sampling methodology to capture disclosure opportunities for Autistic adults.*

Findings from these studies were used to inform the content of three resource guides aimed at making the disclosure process more positive and successful for Autistic people navigating this process and to inform those who support them. Copies of the guides are included in this report.

Study one

Exploring identity importance for Autistic adults and associations with disclosure experiences



What did we want to know?

Is there a link between Autistic identity and disclosure decisions?



111 Autistic adults (63% female, 29% male, 6% non-binary) answered an online questionnaire about their intersecting identities (including Autistic identity) and disclosure decisions.

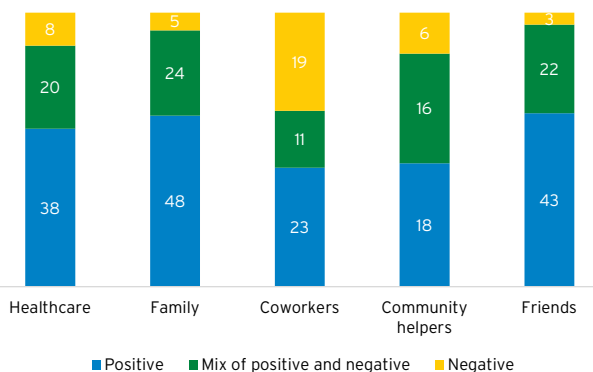


What did we find?

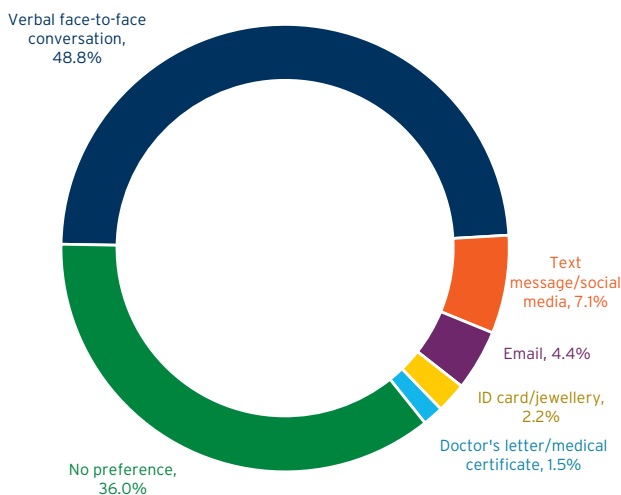
How often do participants disclose that they are Autistic?

- The majority of study participants disclosed that they are Autistic to at least one other person.
- About 33% disclosed to over 75% of their regular contacts.
- 2% of participants had never disclosed that they are Autistic.

What are participants' experiences of disclosing they are Autistic to different people?



What are the preferred methods of disclosure?



How is identity related to disclosure?

We found that if someone feels that their Autistic identity is highly important in their life, they were also more likely to disclose within their social groups. In looking more closely at other identities for our participants, we also learned that Autistic disclosure was more likely for individuals who place a high importance on their sexual identity.

Valuing Autistic identity



More likely to disclose

Valuing sexual identity



More likely to disclose

What are the implications of this research?

Overall, we learned that Autistic people are regularly disclosing across contexts and experience mixed results. We found an association between Autistic identity and disclosure experiences, as participants who disclosed regularly also felt their Autistic identity was highly important.

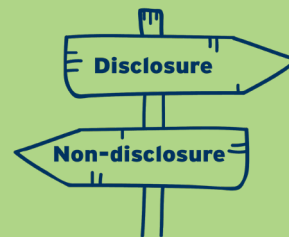


One participant explained that their autism diagnosis helped develop their identity and gave them a sense of belonging:

"I didn't feel I had my own identity until I was diagnosed. I also never felt part of any community until I was diagnosed."

Another participant shared:

"Finally knowing where I fit in life and being able to embrace that and then tell other people about my autism - it all is connected and leads to a greater me."



The findings are important when considering education around disclosure and increased focus on Autistic identity through neurodiversity and elevation of Autistic culture.

The research paper about this study is currently being written. Contact [Abigail Love](#) to obtain a copy once it is published or to find out more about this study.

Study two

Using experience sampling methodology to capture disclosure opportunities for Autistic adults

What did we want to know?

We wanted to know more about the disclosure opportunities (times when people disclose they are Autistic or feel there may be an opportunity but decide not to disclose for a particular reason) of Autistic adults. We chose to study this over a longitudinal period, asking participants to record their opportunities for two months.



36 Autistic adults (58% female, 28% male, 14% non-binary) recorded a total of 231 autism disclosure opportunities:



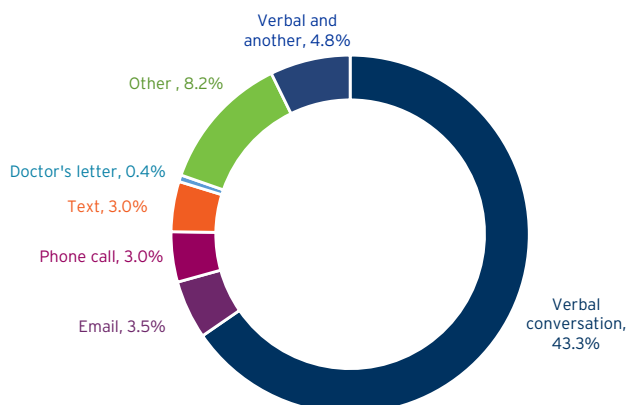
- 153 opportunities were categorised as disclosure, where the participant shared they were Autistic
- 78 opportunities were labelled non-disclosure, where the participant felt there was an opportunity but decided not to share that they were Autistic.

Each participant used a smart phone application to record their thoughts, feelings, behaviours and/or environment in the moment after disclosure. This minimised memory bias and channelled the strength of many Autistic people who are more comfortable, confident and authentic communicating through technology.

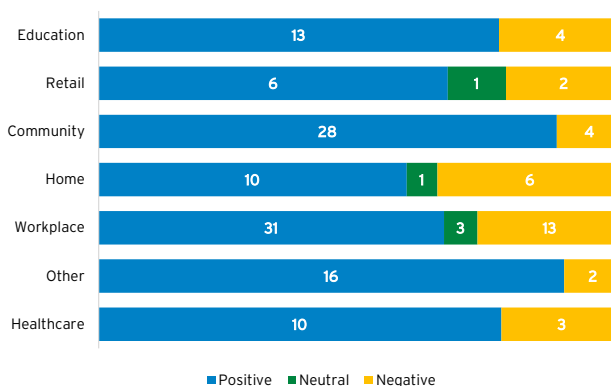


What did we find?

What are the preferred methods of disclosure?



What are participants' disclosure experiences in different settings?



Qualitative findings

Our results were mostly guided by the open responses that participants provided us, as they reported on their disclosure opportunities. From these responses, five themes resulted:

Theme 1: Disclosure led to a wide range of reactions

The reactions of others following disclosure were mixed:

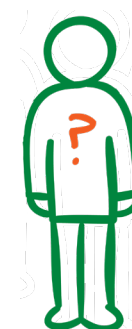
- positive - “liberating not to be judged, but rather encouraged and celebrated”
- neutral - “normal, almost no reaction”
- negative - “felt dismissed and gaslighted”.



Theme 2: What's in it for me?

The decision to disclose or not disclose was influenced by the question “What's in it for me?”

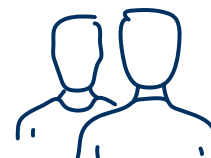
- promoting autism advocacy - “normalise, destigmatise, and challenge people's assumptions about autism”
- becoming more authentic - “it means that I don't need to mask who I am”
- wanting to receive accommodations and support - “more bespoke and accommodating service”
- feeling like there is nothing in it for the participant - “I don't think there was much to gain by disclosing”.



Theme 3: Disclosure decisions are influenced by the context

The people and setting were key determining factors behind whether disclosure felt:

- safe - “I disclosed to my hairdresser who has been doing my hair for over 10 years. He was already aware of all my sensory issues. I felt safe disclosing to him” or
- not safe - “because the individual tends to be quick to judge lots of people and I know they would either not believe me or be rude about it”.



Theme 4: Learning through disclosure experiences

Participants often reflected on their decision and learnt from their disclosure experiences - “It always helps me grow by the reactions I get. What I mean by that is since every time is different. I get different reactions and I am able to help prepare myself for every time I do it. It gets easier to accept peoples either judgement or praises”.



Theme 5: Internal resources are needed for disclosure

Participants thought internal resources may prove helpful in assisting them to decide whether or not to disclose their autism - “I'm not secretive about my autism, but I do choose who, when, and where to disclose. I didn't have the time yesterday to explain what my autism means to my friend, so I'm glad I didn't disclose.” As part of the internal resources required for disclosure, participants often expressed a need for training and support around disclosure - “Some sort of training for these situations would be good as this is common for me”.



What does this study tell us?

Disclosure opportunities are complex! And disclosure outcomes are not black or white - it's not good to always disclose or always not to disclose.

Patterns of disclosure - whether a person chooses to disclose or not - do not need to be consistent over time and across contexts. Until society becomes a truly inclusive environment for the Autistic community, Autistic people should be supported to develop skills to both disclose and not disclose across contexts, with the freedom to change their patterns of disclosure based on important internal and external factors.

We recommend that more support is provided (e.g., within schools, therapy, professional learning) on the disclosure opportunity as a whole, with dedicated space to helping Autistic individuals feel comfortable evaluating their context and internal resources as part of their decision-making process.

Most importantly, work has to be done by the broader community to continue making a more inclusive society where Autistic people can feel safe disclosing if they choose to.

The research paper about this study is currently being written. Contact [Abigail Love](#) to obtain a copy once it is published or to find out more about this study.

Autism disclosure guides

Disclosure opportunities resource guide for Autistic people

Disclosure opportunities resource guide

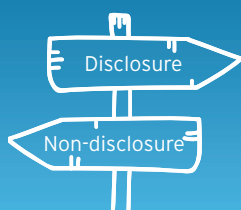
Evidence-based tips for Autistic people considering disclosure

Autistic disclosure is when you consider telling someone that you are Autistic.

Every situation is different, and you can choose what feels right for you every time.

These tips come from people in our study who are Autistic.

Remember: the choice is yours whether you disclose or not.



When considering disclosure:



Do I feel safe to disclose?



Do I have a motivation or reason to disclose?



Do I have the time, energy and emotional capacity to disclose?



Am I prepared for how people might respond?

After a disclosure opportunity:



What can I learn from this experience?

Disclosure is complex and can be hard. We encourage you to talk to someone you trust as you reflect on your experiences, or contact one of these organisations for further support:

- [Beyond Blue](#), phone: 1300 22 46 36
- [Lifeline](#), phone: 13 11 14
- [Headspace](#)

When considering disclosure:



Do I feel safe to disclose?

If you are considering disclosure, think about how safe and included you feel in the current environment and with the people around you. We know society needs to come a long way and some people may not respond well to disclosure. If you feel safe, disclosure might be the right choice and could result in some really positive affirmations from others. If you do not feel safe (trust yourself), non-disclosure (or choosing not to tell someone that you are Autistic) is okay! You may like to help create a safe environment by sharing our *Supporting Autistic people who may want to disclose* guide with non-Autistic people.



Do I have a motivation or reason to disclose?

Some people in our study disclosed their Autistic identity/diagnosis for these reasons:

- To gain accommodations and support
- To advocate for the Autistic community
- To become braver and more authentic in who they are.

If it is important for you to help others learn about autism and to support the movement for autism advocacy, then disclosure could be a pathway for that goal. Telling someone that you are Autistic can bring a sense of belonging, can help you feel heard, and can lead to shared experiences with others. Many people find it means that you can [mask](#) less and be your authentic self. Disclosure can also be about getting support, helping people understand who you are, and what accommodations you need to thrive. Autism self-advocate and social justice influencer, [Autiennele](#) shares her [thoughts on autism advocacy](#).

You might disclose for another reason, and that is okay too. If you don't have a motivation or reason to disclose, it is okay not to disclose as well.



Do I have the time, energy and emotional capacity to disclose?

Having the time, energy and emotional capacity as well as a general sense of well-being or feeling okay can help you have a positive disclosure experience. Learn to consider your internal resources and decide if you have enough of what you need to disclose or talk about the fact that you are Autistic. Often, you may feel too tired, emotionally spent or at risk of [burnout](#), and that is okay. Have you read about the [spoon theory](#)? It is a really great way to think about your own resources!



Am I prepared for how people might respond?

What sort of reaction do you expect? What happens if the reaction is negative? Or unexpected? People are going to react in all sorts of ways! The response of the other person(s) to your disclosure may be positive, neutral or negative. Unfortunately, some Autistic people have negative disclosure experiences. To prepare for these reactions, you could practise writing a script or role play the situation with someone you trust. It can also help to talk to someone who has already navigated this process! Or, look at the examples on page 3 for ideas on how you might respond in different disclosure situations.



What can I learn from this experience?

Our participants shared how reflection led to learning. Often individuals would reflect and think about how disclosure could have led to support - like one participant who said they wish they had disclosed at the airport to avoid crowds and discomfort. While others did disclose, and reflected on their negative experience and how they would be more careful in the future. Every situation is different, and sometimes you have to trust yourself as to whether the possible benefits outweigh the possible risks.



Keep this guide handy!
Download and add it to your
mobile phone home screen



Here are some real-life disclosure scenarios that Autistic people shared with us. We asked our Autistic researchers and Autistic advisors to offer their suggestions for what they might say or do. These examples may help you prepare or give you ideas on how you can respond.

Possible scenarios	Possible responses
The other person was shocked and asked how could I be a hairdresser if I was Autistic?	"Well actually, Autistic people can bring a range of strengths to any workplace or role."
They gave me an odd look and didn't respond.	It would take more resources than I have to continue a conversation with this stranger - its best if I just finish my shopping and leave them.
They were shocked, they didn't believe me.	I would take a breath to calm myself (if I become emotional, they will become emotional) before responding with what autism is and what it means to me. "Autism is a lot different from how it is portrayed in TV and movies. The original diagnostic criteria were based off young boys. if you do some research I think you will find many people are discovering they are Autistic later in life now especially women and non-binary people."
They didn't really acknowledge it and just kind of ended the text exchange.	Maybe this isn't the workplace or co-worker I need in my life if they can't accept me.
They complimented me and said I should be proud that I have a job.	As this is my workplace, I would need to pause before responding professionally and challenging their assumptions about autism.
They asked, "Isn't everybody a little Autistic?"	"Well actually, implying that everybody is Autistic is harmful to the experiences of Autistic people ... it would be like comparing my headaches to somebody's experiences of chronic cluster migraines."
They challenged me, "But HOW are you Autistic? You can't be Autistic, you are so outgoing."	I would need to think what to say next, but first I would challenge them by asking why they thought I was not Autistic. That is to learn their concept of autism and what autism looks like to them.
Positive, expressed thanks for sharing, advised it was 'good to know', gives better insight for accommodations I might need	"Thank you, having accommodations and my needs met will allow me to give my best work in this role."
They wished that I disclosed to them earlier.	"Disclosing being Autistic is a private and personal decision."
They nodded and thanked me for telling them.	"Thank you for accepting me."
They took it well and had some questions, one person said they wouldn't have guessed I was Autistic.	"Thank you for your interest - as an invisible disability, you can't simply spot an Autistic person or know their story by looking at them."

Disclosure opportunities resource guide for Autistic people (Easy English)



What should I do if I want to tell someone I am Autistic?

Disclosure is telling someone that I am Autistic.



Non-disclosure is choosing not to tell someone I am Autistic.

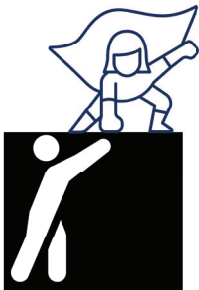
The choice is mine.



What should I think about if I want to disclose that I am Autistic?



1. Do I feel safe?
 - The place is safe
 - The people I'm with make me feel safe



2. Do I have a reason?
 - I want help
 - I want to be brave
 - I want to help the Autistic community



3. Do I feel okay?
 - I have enough energy
 - I have enough time



4. Am I prepared for how people might respond?
 - It could be good
 - It could be bad
 - It could be neutral
 - Some people might not know how to respond



After a disclosure opportunity:

5. What can I learn?
 - What went well?
 - What went bad?
 - What can I do differently next time?

Here are some examples of how you could respond.

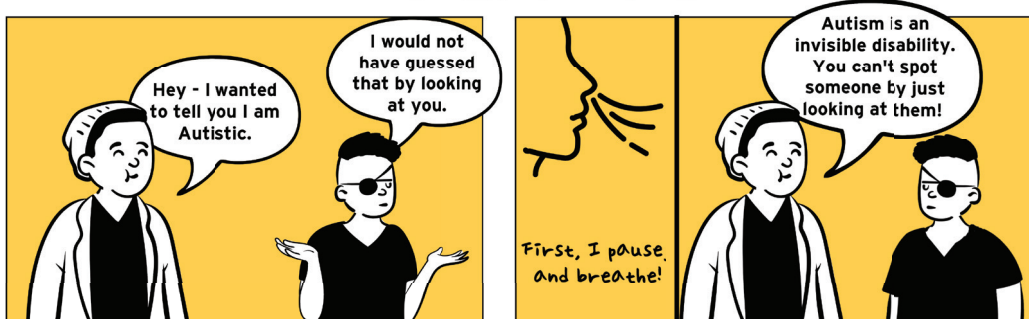
THIS WENT WELL!



SOMETIMES PEOPLE JUST DON'T KNOW MUCH ABOUT AUTISM



IT IS OKAY TO PAUSE, AND BREATHE



Supporting Autistic people who may want to disclose – tips for non-Autistic people

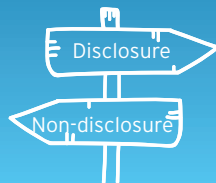
Supporting Autistic people who may want to disclose

Tips for non-Autistic people

Autistic disclosure is when someone chooses to disclose their Autistic identity. While disclosure is a personal choice, it is everyone's responsibility to create an environment where Autistic people (and people with other disabilities) can feel safe to disclose and be their authentic selves.

To be an ally or an advocate to someone who wants to talk about autism, follow these tips from people who are Autistic!

Disclosure is private. If somebody discloses to you, that is a private decision and it is not for you to share with other people unless that person gives you permission to do so.



Ensure you create a safe environment

- Welcome open conversations about disability and neurodiversity
- Consider how sensory-friendly your environment is (do you need an expert to assist?)
- Treat all people with respect
- Value perspectives that might be different to your own



Words and responses matter!

Some of the most negative reactions as reported by Autistic people following their disclosure included people:

- Telling me, "You don't look Autistic!" or "There is no way you could be Autistic!"
- Being shocked or surprised
- Responding with disbelief saying I don't have it ...
- Dismissing what I had to say



React positively

Some of the most positive reactions as reported by Autistic people following their disclosure included people:

- Making me feel welcome
- Being curious, interested and excited
- Making me feel heard and understood
- Thanking me for sharing being Autistic
- Making me feel valued and seeing my autism as a strength
- Asking how I experience things
- Asking me for resources about autism



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a different brilliant[®]

understanding, engaging & celebrating the
strengths, interests & aspirations
of people on the autism spectrum

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