



Welcome to the Autistic Community: A Welcome Pack

Prepared by

The Intersectional Advisory Committee (IAC)
March 2024

Acknowledgement of Country



(c) Jordan Adler, 2021

Always was, always will be, Aboriginal land. We acknowledge the Traditional Custodians of the lands on which this Welcome Pack was created and pay respects to Elders past and present. We extend that respect to all Aboriginal and Torres Strait Islander people.
Sovereignty was never ceded.

We acknowledge First Nations' ancient connection to storytelling as we share our Autistic stories and how these shape our world and our connections to it.



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Welcome!



Welcome



Congratulations – You're Autistic!

"If you find out that you're Autistic later in life, it does not change who you are. In fact, it doesn't change who you are regardless of 'if' or 'when' you find out. Your neurotype has been with you since birth; it is you. What that recognition does, however, is give you the opportunity to start to see yourself in a different light, in a way that is more inclusive, compassionate, forgiving and loving. It gives you the chance to understand yourself better, through a new, more accurate lens. That chance is worth so much more than you could ever know. It can be literally life changing.

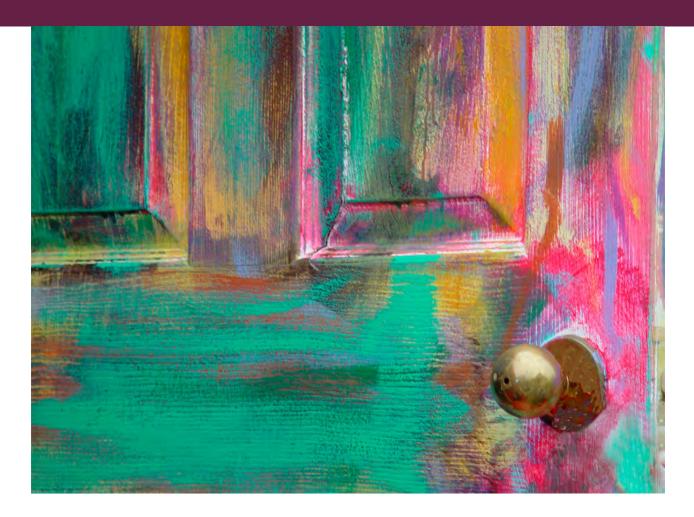
You are absolutely entitled to the freedom to be exactly who you need to be, and to be unapologetically you. Your neurotype makes you no less of a capable and worthy human being. You are entitled to access supports and adjustments to allow you to thrive in your environment. You are entitled to feel loved and safe, heard and seen. You are enough, just as you are.

There does not need to be any stigma around being Autistic. Educate yourself from the perspective of others with lived experience. Listen to them and learn. We all have a responsibility to learn and to contribute to that educational piece; sharing our experiences as Autistic individuals and being involved in the dialogue helps to work towards creating a more accepting and understanding world."

- Sarah Climpson



Welcome



How to use the Welcome Pack

Whether you have suspected you are Autistic for a while, or are brand new to your Autism journey, we hope you feel welcomed to the Autistic community through exploring this document, Reframing Autism's 'Welcome Pack'.

We invite you to engage with this Welcome Pack in whatever way works for you. You might like to read in full, from start to finish, or dip in and out at bits that interest you.

We have resisted summarising our Welcome to you in a single page, because we want to avoid simplifying our stories to fit neatly into a public-facing document.

We therefore share our unique collection of Autistic stories in their complexity, with their contradictions, tensions, and humanity. We have not smoothed over these tensions to condense key messages, because we know our decisions as coauthors matter. What stories we feature, exclude, and how we order and present the information is all an exercise of power.

In reframing Autism, we deliberately move beyond traditional power dynamics to offer you insights into what we have learned about Autism in a way that centres our community's voices, as well as those who are reading it. So, we invite you to dive in and explore as you like.

You each will bring your own lived experience of Autism. You may feel more aligned with some stories than others. Our different voices are enormously valuable within the spectrum that is Autism.

We hope you enjoy exploring our Autistic insights as much as we have.

Capturing your own reflections

The following sections gather Autistic people's stories and experiences of their Autistic identity together, to help you in thinking about your own Autistic identity. We invite you to consider what that means for you, and to you.

Within each section, we have included some specific reflection prompts for you to consider. Whether, and how, you engage with these prompts is up to you.

If you would like to type your thoughts and reflections when prompted, we encourage you to download the Word document or Welcome Pack Workbook here. The Workbook is a 'fillable' PDF and enables you type directly into the

document. This means that you can share your Welcome Pack with friends, families and allies, without needing to share your intimate thoughts and reflections, which can be captured separately in the PDF Workbook or Word document.

Whether you ignore the reflection prompts, respond formally to them in writing in the PDF Workbook or the accessible Word document, discuss them with a trusted supporter, friend or therapist, or just think on them internally, we encourage you to take the time and space you need to consider the stories we share, and how they might apply or resonate with you and your experiences, past and present.



Glossary of terms

We'd like to take a moment to let you know about our position around the use of certain language. We embrace the neurodiversity* paradigm. This takes the basic concept of neurodiversity ("all brains are different") and proposes that some brains are neurotypical* (that is, broadly conforming to a standardised, typically developing norm), and some brains are neurodivergent* (that is, diverging from that standardised, typically developing norm). Regardless of whether neurotypical or neurodivergent, all brains are valued.

Importantly, the neurodiversity paradigm argues that divergent brains – and, by natural extension, Autistic brains – should exist alongside neurotypical brains, without judgement. We are not 'disordered' (a subjective judgement) because of our neurodivergence*. It proposes that typically developing brains are no more 'right' or 'desirable' than divergent brains.

We also reject the use of potentially

harmful therapies, which are those therapies that are intensive in nature or promote Autistic masking* or the suppression of Autistic behaviours.

Because this position is foundational to the Welcome Pack and our work at Reframing Autism, many of the words we use and the definitions we adopt in this Pack are constructed within this lens.

In this Welcome Pack, then, you might come across some terms, concepts or acronyms that are unfamiliar. These words will be marked with an asterisk (*). You'll find a handy glossary of these words on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/.

If there's anything missing from this list, or if there's anything you'd like to enquire about, please get in touch with us here: https://reframingautism.org.au/contact/.

We're always happy to help!



Creating the Welcome Pack



Acknowledgement of Contributors

This Welcome Pack for newly diagnosed Autists would not be what it is without the contributions of many.

Our Intersectional Advisory Committee (IAC) is comprised of community representatives from under-represented and multiply marginalised groups to help us understand better how we can support the full breadth of our community. It is these extraordinary individuals who have contributed to this Welcome Pack, to make it what it is.

If you'd like to know more about our IAC members, you can read their biographies from page 181 of the Welcome Pack.

Thank you to the richness of our Autistic community's voices, which created the storied pieces you will find throughout this Pack.

Those voices include:

- Alexandra Johnston ^
- Alex Pilgrim
- Charlie Park
- Ginny Grant ^
- Hem (aka Sid) Chandran
- Jenny Mitchell
- Natasha Siryj ^
- Sarah Climpson ^
- Shazzy Tharby
- Stormy Meiying Liu
- Tim and Sarah Chan



^ We extend our gratitude to IAC Chair, **Natasha Siryj**, who facilitated meetings and supported the co-design process, and to **Sarah Climpson**, who assisted with editing this document. A special thank you to **Dr Alexandra Johnston** and to both current and former Reframing Autism employees who played an integral role in creating and shaping this Welcome Pack so it can be shared with the world.

While Ginny Grant is not a member of the IAC, she has given permission for her written content (as featured on the Reframing Autism website) to be utilised in this project.





How we worked together

Essential to this Welcome Pack is not just the 'what' behind the stories we discovered, but 'how' those stories were discovered.

We sought to create ways of working that were open and inclusive, sharing our learnings, mistakes, and emerging insights.

The contributors to the Welcome Pack were invited to a series of meetings and workshops where we collectively identified and reiterated key themes and insights.

We shared an early draft of this Welcome Pack with everyone who contributed, inviting them to ask questions, offer comments, and highlight points we had either missed or misconstrued.

Our project team met every few weeks to deepen our relationships and share our journey of discovery. We also spent time upfront defining how we wanted to work together as a team to support the Welcome Pack co-design.

A key insight from listening to our Autistic community was the importance of holding contradictions in our stories rather than smoothing these over. We have tried to honour that approach in this Welcome Pack.





The insights from our co-design work are organised around five main questions:

- How did you experience discovering you are Autistic?
- 2. Why is building Autism acceptance and self-compassion important to you?
- 3. How can we each develop a positive Autistic identity?
- 4. What can we do to reduce masking* and camouflaging?
- 5. How can each of us live a good Autistic life?

We discovered so many other insights, we also wanted to share these with you, including:

- What we wish we had known
- What we want others to know

These questions were incredibly important to our Autistic community members as they explored their own Autistic identity. We have used these questions to form the main sections of the Welcome Pack, which is shaped to help you to consider and perhaps answer these questions for yourself.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



We have used many different sources and resources to shape and develop this Welcome Pack.

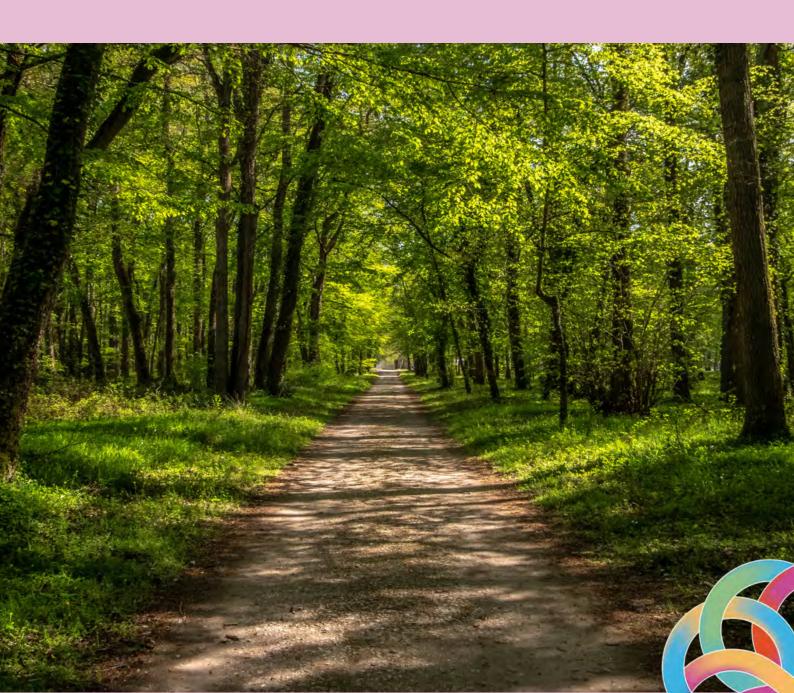
Primarily, the stories you will read within this Welcome Pack are drawn from the insights of members of Reframing Autism's Intersectional Advisory Committee (you can read about this committee on page 10).

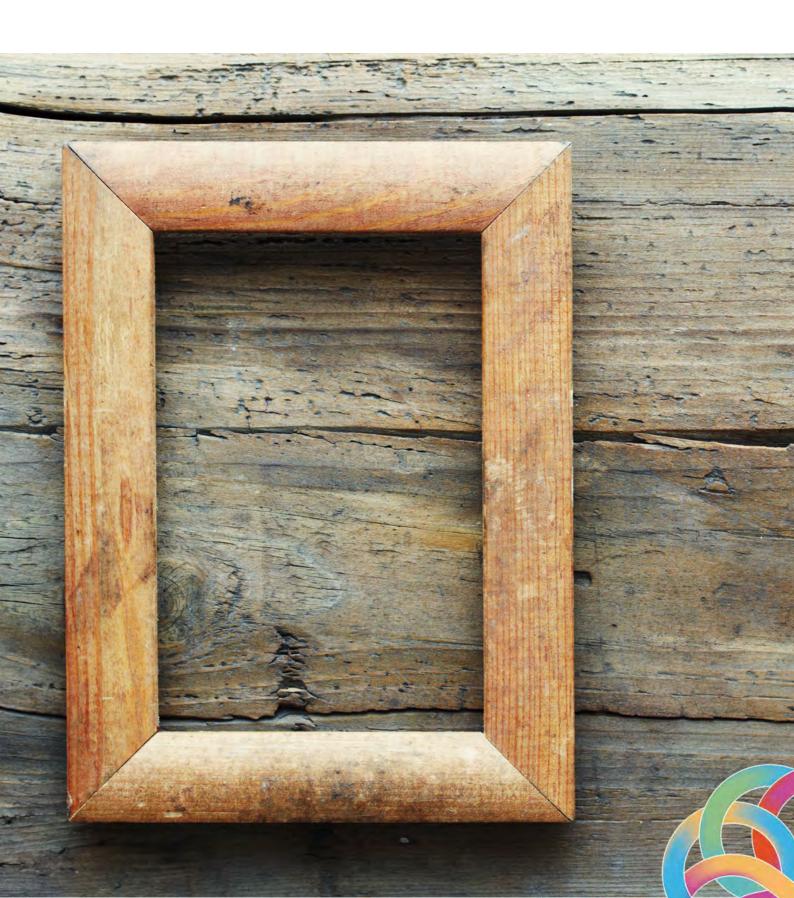
We have also drawn on the vast literature and expertise that already exists, including the Reframing Autism website: https://reframingautism.org.au/.

In the next section of the Welcome Pack (starting on page 14), we have used information from Reframing Autism to talk more about our how (and why) we 'reframe' Autism.

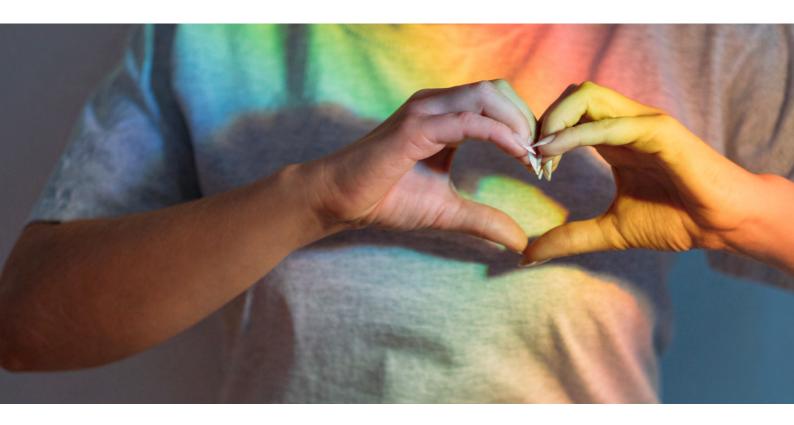
In the subsequent sections (beginning with Part one, on 'Discovering you are Autistic', on page 30), you can read our stories, insights and tips.

We've listed some other resources we drew from, and that you might like to explore yourself, in the resources list on page 176.





In this section, Reframing Autism, we touch on the following:



- What we mean by 'reframing Autism',
- Neuro-developmental differences,
- Identity-first language,
- Autism as a difference,
- The differences of an Autistic brain,
- Neurodiversity* as a concept,

- The double empathy problem,
- How Autism can be missed,
- Autism as a part of human diversity,
- Learning about Autism,
- Reframing your life as an Autistic, and
- Every Autistic person is unique.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



What do we mean by 'reframing Autism'?

How we understand and view Autism is potentially different to the views you have heard elsewhere. You can read more about how we think about Autism on Reframing Autism's 'About Autism' page.

Reframing Autism is an Autistic-led charity, whose mission it is to reframe the understanding of Autism through education, resources and research. Our perspectives on Autism don't just come from professional training or book-learning. They come from our lived experiences as professionals, as parents, and, most importantly, as Autistic people.

We have lived as Autistic individuals our entire lives, and we each have a deep, personal knowledge of what it is to live Autistically.

It is that experience that informs what we do and why we do it.



Reflection

To start, you might like to take a moment to consider where your information about Autism comes from, how you currently think about Autism, and how this might contribute to the way you feel about realising you are Autistic.

If you like, you can note your thoughts on page 5 of the Workbook.



Autism is a neuro-developmental difference

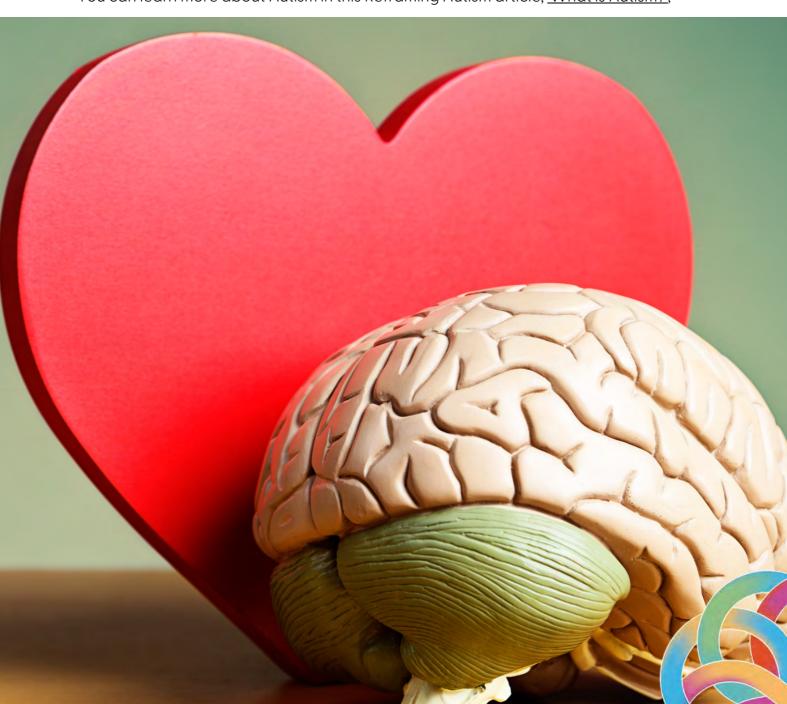
Did you know that **Autism is not a disease**? Autistic people are not ill because of their Autism. Autism cannot be diagnosed with a blood test or "cured" with medicine.

Rather, **Autism is a neuro-developmental difference** that can manifest itself in communication differences or differences in social skills and interaction.

Because Autism is part of everything we experience and the way we are in the world, it is an important part of our identity.

We cannot imagine an Autistic person without their Autism.

You can learn more about Autism in this Reframing Autism article, 'What is Autism?',



We use identity-first language

At Reframing Autism, we use identity-first language: "I am Autistic" rather than "I have Autism". This reflects the preference of the majority of our Autistic community and shows that we understand Autism as a neuro-developmental difference, not a disease (see p. 18).

We also uphold the absolute right of everyone to self-identify in any way they may choose.

We do not use traditional, pathologised language to distance Autism from a disease.

So, Autism is not a 'deficit' or a 'disorder'; it is a difference.

We reject functioning labels: these labels are degrading, dehumanising and reductive, and there is no such thing as a 'high functioning' or a 'low functioning' Autistic.

We do not use the outdated and problematic term 'Asperger's syndrome' or 'Aspie'.

You might like to explore more about how language helps shape identity in this article on 'Neurodiversity-affirming language'.

We think of Autism as a difference

This means that Autism is an important part of who we are and the way we are in the world. It is a fundamental part of us.

Autistic people develop differently to nonautistic people. Autistic people think, move, interact, sense and process differently to what people might expect.

We also have more qualities and characteristics in common with other Autistic people than with non-autistic people. Each person is different, but Autistic people will be different to non-autistic people in the way we:

- Socialise and communicate, including the way we connect, make and understand friendships and relationships, and use speech and body language.
- Think and process, including the way
 we see patterns and connections,
 imagine and play, experience and
 express our senses, emotions and
 executive functioning, and in the way
 our brains develop.
- These differences can look different for children and adults.

If you are looking for further information, you might like to continue to learn more about Autism using our further resources on page 176, or on the Reframing Autism website, on our 'About Autism' page, or 'Lam newly diagnosed' page.





My Autistic brain makes me different

"I'm no superhero and I definitely do not have superpowers! I'm just an average Autistic person.

Sure, there are Autistic people with very high cognitive abilities and epic memory skills. We need to stop being surprised at this. There are a few geniuses in the Autistic population just like there are a few in the neurotypical* population.

My Autistic brain makes me much better at some things and much worse at others compared to neurotypical people. For example, I'm very good at visual problemsolving, but I have always struggled with mental arithmetic.

Measured by neurotypical standards, my school performance was inconsistent.

I don't think this means that my strengths are superpowers. Stick me in a school of all Autistic students, test me against Autistic standards and I bet I'm average. It's the education system needs to change to recognise a broader range of brains and ability profiles.

My Autistic brain makes me different, not exceptional."

- Charlie Park

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Neurodiversity and the neurodiversity paradigm

This Welcome Pack approaches Autism from within the framework of the neurodiversity paradiam*.

Neurodiversity* is a concept that emerged in neurodivergent*-led online spaces in the late 1990s. It was then popularised by the journalist, Harvey Blume, after the Australian sociologist, Judy Singer expounded it in her thesis. Neurodiversity simply refers to the reality that a diversity of human brains and minds exist.

It is a biological fact that each person's brain is different, since the brain is a complex organ that develops through a continuing interaction between a person's genetics and their experiences and environment.

The neurodiversity paradigm offers us a framework by which as Autistics, we can celebrate who we are, how we exist, and what we have to offer. Neurodiversity allows us to be our whole authentic selves because of our differences, not despite them. You can learn more about neurodiversity in this article.

The neurodiversity paradigm asks that neurodivergences* be considered without judgement; it advocates for abandoning models that construct neurodivergence as 'less than', 'defective', 'broken'.



* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Neurodiversity*:

- Separates neurology from disorder
- Respects and accepts neurological differences
- Confronts neuronormative* privilege
- Responds to all needs, and accepts them as valid
- Recognises and addresses ableism*
- Values thinking differently

You can learn more about neurodiversity in this <u>blog</u> and this <u>information article</u>.



^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



The double empathy problem

Damian Milton (2012) is an Autistic Autism researcher from the United Kingdom. He argues that Autistic people experience the world and express emotions differently to non-autistic people. We communicate, experience and display emotions, interact with others, form relationships, and sense the world around us, differently to non-autistics. That doesn't mean that we don't have emotions or feel empathy.

But it makes it difficult for non-autistic people to understand and to empathise with us, and us with them. Just as it is said that Autistic people lack 'social insight' into non-autistic culture and communication, it could also be said that non-autistic people lack 'social insight' into Autistic culture and communication.

Milton calls this disconnect a 'double empathy problem', because both Autistic and non-autistic people experience a lack of understanding for the other group.

You can learn more about the double empathy problem in this <u>lay summary</u> of Damian Milton's argument.



How Autism might be missed across demographics

Autism has historically been more frequently identified in young, white males. In fact, the diagnostic criteria for Autism have developed from a androcentric (male-focused), childhood perspective. So, diagnosis is skewed to identify Autism in certain demographics of children.

Autism, however, doesn't discriminate, and is experienced in people across genders and races, despite the fact our diagnostic processes are not always sensitive to gender, racial or cultural (or other intersectional) nuances.

Currently, diagnosis focuses on external, observable behaviours. When we think that children are socialised to behave differently depending on many factors, including gender and culture, it helps us to understand how Autism might be missed in many demographics.

Research is continuing in this area, as more people of all genders and backgrounds identify as Autistic.





Autism is a part of human diversity

"I hate the phrase 'Autism epidemic'. It perpetuates the idea that Autism is a nasty disease that needs to be eradicated. Autism is actually a type of brain and resulting thinking/feelings/behaviours caused by genes.

In his book Neurotribes, Steve Silberman argues that Autism has been around for centuries: it probably started as a random gene mutation. The resulting brain structure and way of thinking must have had survival and community value, because it's persisted. Autism has become a permanent part of human diversity.

That paediatric psychiatry only identified, named and started diagnosing Autism in the 1940s, doesn't change that there were Autistic folk before this - they just weren't called Autistic.

That paediatric psychiatry initially mistakenly thought that Autism was a mental disorder and their diagnostic criteria was designed to pick out children for institutionalisation or treatment, does not change that there was a whole big population of Autistic folk out in the community that were missed.

That it's only now starting to become safer to identity as Autistic (with less risk of institutionalisation, discrimination or hatred), means that diagnosis and self-identification are only now starting to correctly capture the whole population.

We are stepping out of the shadows, dropping our social masks and embracing our true natures."

- Charlie Park

Learning about Autism can be validating

"Autism affects how people behave and interact with the world around them. Autism can present differently in different people, there are some things that we share, but generally, not everyone has all.

Common traits may include:

- Difficulty with eye contact, perhaps you look at people in between their eyes, forehead or nose, or struggle to maintain eye contact. For many of us eye contact can feel very uncomfortable, and we can end up focusing on the need to get eye contact 'right' and totally miss what is happening in the interaction or conversation.
- Social differences, perhaps you like alone time and enjoy being by yourself more than most people? Perhaps you struggle to engage in busy, loud social settings with lots of people and prefer one on one engagement, or maybe you are more comfortable with online friends. Many of us Autistics have a way of being that may be considered different to the norm, which of course is totally alright! Embrace your Autistic self!

- Many late-identified
 Autistic adults go
 through a period of selfreflection and life
 reframing after
 identifying as Autistic.
 Charlie Park
 - Sensory issues, perhaps you find it hard to wear certain clothing or shoes or eat certain foods. Perhaps you find offence in strong smells or cold water. Many Autistics have sensory issues and things that we avoid. Some of these things can cause us physical pain and send us into a meltdown or overwhelmed state.

Learning about Autism can help you to understand yourself better, it can be very validating."

- Natasha Siryj



Reframing your life with Autism can involve:

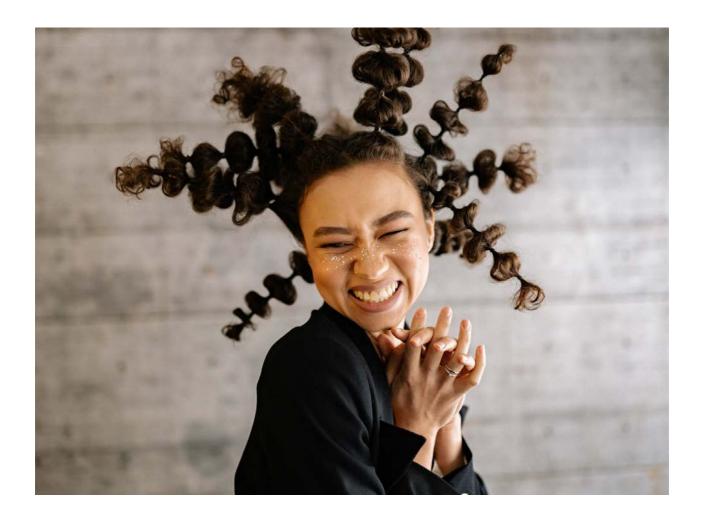


- Redefining what you think Autism is and what it means for you.
 - Learning how the Autistic experience differs from the Allistic* experience. For example, discovering that the way that you experience environments is completely different louder, smellier, brighter – than how Allistic people experience the same environment.
 - Reliving past experiences with the new lens of knowing that you are Autistic and have a different brain to most people around you.
 - Finding out that you have coconditions such as ADHD, connective tissue disorders, OCD, epilepsy, dyspraxia, dyslexia, and/or pathological demand avoidance.
 - Learning it's normal for Autistic people to have spikey skills profiles when assessed against neurotypical standards. Just because you are struggling with one task and not others, doesn't mean that you are not trying your best or you are incompetent.
 - Realising how often miscommunications occur between Allistic and Autistic people because of the 'double empathy problem*'.

- Learning that you were doing a lot of social masking* to try to fit in or do the right thing, and this is exhausting and unnatural for Autistics.
- Learning new words to describe experiences that were previously confusing to you and now you know are normal Autistic experiences. For example: 'Autistic burnout*'. 'meltdown*', 'stimming*', 'face blindness'.
- Realising that you were mistreated, taken advantage of, bullied, abused and/or discriminated against because of your Autism. This may have been by teachers, doctors and other people in authority.
- Gaining insight into past social interactions that were confusing and/or distressing.
- Questioning your gender and/or sexuality.
- Realising that you are not 'rude', 'snobby', 'annoying', 'blunt', 'oppositional', 'gullible', 'childish', 'slow', 'weird' and all of the negative things people might have called you over the years. You are Autistic!
- Charlie Park

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Every Autistic person is unique

Just like every person, every Autistic person is unique and has different abilities, interests, and challenges. Each Autistic person will experience their Autism differently, including in the way they communicate, socialise, and interpret sensory stimuli.

No person, whether they are Autistic or not, is naturally skilled at everything. All of us have skills and challenges, and areas where we need more (or less!) support. This is as true for Autistic people as it is for non-autistic people, and each Autistic person is an individual with their own profile of skills and challenges.

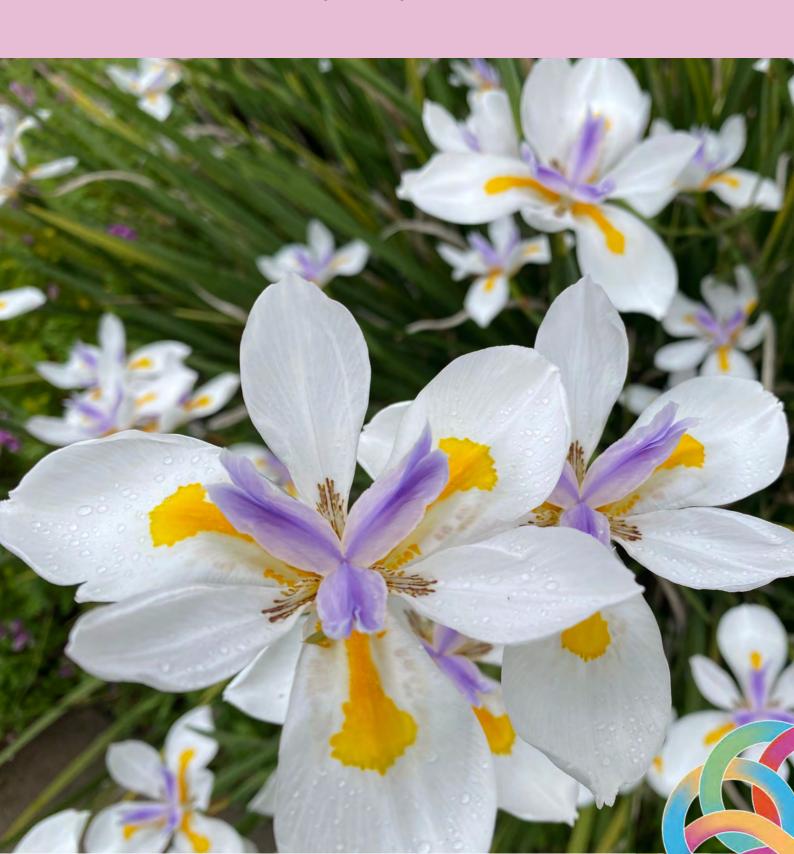
•• If you've met one individual with Autism, you've met one individual with Autism.

> - Dr Stephen Shore Autistic advocate and academic

Reflection

Take a moment to consider how your Autistic brain makes you unique and different, and, if you're ready, some of your strengths, skills, and challenges.

If you like, you can note your thoughts on page 6 of the Workbook.



Part one: Discovering you are Autistic





In Part one: Discovering you are Autistic, we touch on the following:

- Having a new lens to understand yourself,
- Initial responses to an Autism diagnosis,
- Experiences of diagnosis and the start of ongoing discovery about yourself,
- All Autistic people are unique and different,
- Benefits of diagnosis, including increased self-understanding,
- Strategies for processing a diagnosis,
- The importance of understanding and information early in the process,
- Navigating community following diagnosis, and
- Barriers to diagnosis and the role of self-identification.



A new lens to understand yourself

Even if you were only diagnosed a few hours ago, you've been Autistic your whole life! So, although having a whole new lens through which to understand yourself can feel daunting and perhaps a little scary, realistically, you've been getting to know yourself for your whole life. The difference is that now, you have a better understanding of what makes you, you!

Even if you were only diagnosed a few hours ago, you've been Autistic your whole life! The difference is that now, you have a better understanding of what makes you, you!



There is no right or wrong thing to do at this early stage... many of us who have been diagnosed later in life take some time to reassess some key moments in our past. But before you do that, you might like to take some time to learn about Autism, so you can reflect on the ways that it might have shaped your life.

Autism plays a role in your social skills, communication, sensory perceptions, interests, hobbies and executive functioning – among many other things! The more research you can do, and the more you can access the experiences of other Autistics, the more "aha!" moments you'll be able to have on your journey to understanding how to help yourself flourish.

Building resilience and practicing selfadvocacy is incredibly important for Autistic people – so the more understanding you can garner about your own amazing neurobiology*, the better placed you are.

Learn more about Autism at the Reframing Autism 'About Autism' page.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Initial responses to an Autism diagnosis

A new Autism diagnosis (or the epiphany that you are Autistic) can be very validating. Some Autists describe it as feeling like "finally coming home to myself".

However, that same identification might also lead you to question or reassess some things in your life. As you adjust to your 'new normal', it is common to feel upsidedown, confused, shame, or in flux.

Many Autistic people find that, once diagnosed, the relationships in their lives become a big focus, as dynamics in relationships can change.

Some people in your life might not understand Autism or may only know about it from the harmful stereotypes and caricatures that they've seen in the media.

The misconceptions around Autism that still permeate many people's understanding are often due to a lack of knowledge. It may be ignorance, but it can feel cruel and still hurts. You may feel burdened to educate your family, friends, and colleagues.

You can learn more about navigating being identified as Autistic in adulthood and what Autism might mean for you - in this <u>article</u> on Reframing Autism's website.



My experience of diagnosis: Sarah's story

"I found out I was Autistic and had ADHD when I was 32 years old. My husband and I supported our eldest child through the formal assessment process [when] our child was 3.5 years old. When we learned of his Autistic identity, things suddenly made lots of sense for my own life; this is when I decided to go through the formal assessment pathway.

I was privileged enough to be able to afford this expense and was even more fortunate to have landed on a clinical psychologist who was entirely, genuinely neuroaffirming*. As a consequence, I found the assessment process to be very positive, supporting and liberating. Having a 'label' meant that I was able to realise who I truly was. It meant that the negative self-talk in my brain and the comparison I did between myself and others was put into perspective. I realised that years of 'you should be able to do...' statements were always going to bring on disappointment.

No matter how hard I tried, no matter how many strategies I put in place, I always felt like I was never able to do some of the things or cope in the same way as others. After my identity was revealed, I was able to understand why and start to embrace the traits that were strengths and the things that made me different. I started to do a lot of reading about autism and ADHD, and how the two neurotypes* presented, and how different things might look when they intersected. I often refer to my brain as having two halves; my ADHD half and my Autistic half.

I never even realised I was ADHD, never thought of myself as having any traits; it was not until I went for my autism assessment that the clinical psychologist suggested we test for both after a passing comment I made about my brain state.

Once I started reading and learning more about ADHD, everything properly made sense.

The two halves of my brain cancel each other out at times, it's pretty interesting living inside my mind. It can make it easier in some respects, but at times it makes it really difficult to manage daily life. I still don't quite understand my brain fully, but I have come to love it a lot more since my assessment.

There are a lot of things I can do very well and when I am in the right environment, but there are also a lot of things that I struggle with. I am very lucky that I have a supportive husband and friends around me who can work with me to fill in the gaps.

When I am overwhelmed and have not had time to engage in deep interests and regulate, I have trouble with daily tasks and executive function. That makes it hard for me to be the best version of myself, especially as a parent. My son and daughter are both ND*, and I also live with a physical disability.

Our family life is chaotic at the best of times, and juggling my chronic health conditions, disability, neurotype, parenting, maintaining relationships and holding down a professional job is exhausting.

I don't often have time for deep interests, and I suffer greatly because of that. I am still learning how to balance all the

... continued on p. 35

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

... continued from p. 34

demands that are placed on my already fractured and struggling brain.

I went through a stage of intense burnout that lasted over 12 months and resulted in me having to take significant time off work, modify my work duties upon return and engage in frequent therapy.

I didn't realise at the time this was Autistic burnout*, because I didn't yet know I was Autistic. I can see why and how it came about, but it was so difficult to go through because I thought something was terribly wrong with me. I just couldn't function, at all.

Time and space and support is what got me through, and a bunch of self-care that I would not have been able to do if I was not given time off work. I am so lucky to have such an amazing support network around me; I know not everyone has the same.

Despite the daily struggles, I am a proud ND* woman and I use my voice to advocate for neuroaffirming* practice in the workplace, and when parenting. I believe strongly in challenging social stereotypes and get involved in change pieces whenever I can.

Finding out I was Autistic has allowed me to really accept myself and honour my own needs; that's not perfect, and it's a work in progress, but it's absolutely better than it was before.

That's why I believe so strongly in making the assessment (diagnostic) process accessible for everyone, equally. Feeling validated and whole is undeniably critical to living a holistic human existence."

- Sarah Climpson



You can learn more about Autistic burnout in this blog.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Diagnosis is only the start of the discovery process

"I was not diagnosed as an adult. I was diagnosed as a child. But I had my own discovery process. I was six when I became aware that I was neurodivergent*. I have spoken about the way it affected in my book.

My knowledge of neurodivergence* came to me when I was 6 years old although my family and my network knew this when I was 2. I can remember my feelings about my being different and how I felt when I was 6.

As I grew older I began to realise that although I was non-speaking*, I had an understanding of what was going on around me and how words [work] and what they meant.

This knowledge grew stronger till some years later I 'told' my mother that I could spell and read and communicate with her. This was for me an 'aha' moment and I think that might be similar to how others deal with an adult diagnosis and self-discovery of autism as an adult."

- Hem (aka Sid) Chandran

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Autistic people are all different

"But you don't look Autistic' is one of the most common responses to coming out as Autistic in adulthood. It's dismissive, rude and plain wrong. Most people seem to have a fixed image of what Autism looks like based on characters they've seen on TV and in movies, or from stories on the news.

But this is a stereotype - based on exaggerated characters made up by nonautistic actors and sensationalist news stories about missing Autistic boys.

If you want to 'see' real Autistic people, watch:

- 1. Chloe Hayden's character Quinni in Heart Break High on Netflix.
- 2. The stand-up comedy 'Douglas' by Hannah Gadsby.

3. The documentary 'The Reason Why I Jump'. It's about the memoir of Naoki Higsahida, a then 13-year-old non-verbal Autistic boy.

The reality is that Autistic people come in all different shapes, sizes, genders and races with different ways of moving, behaving and communicating, and different co-conditions.

What we all have in common is a similar brain structure. How this 'looks' is different on everyone. Plus, many Autistic adults learn/are taught to camouflage - we hide our visible differences to keep safe and fit into a neurotypical* world. Spotting an Autistic person isn't easy."

- Charlie Park



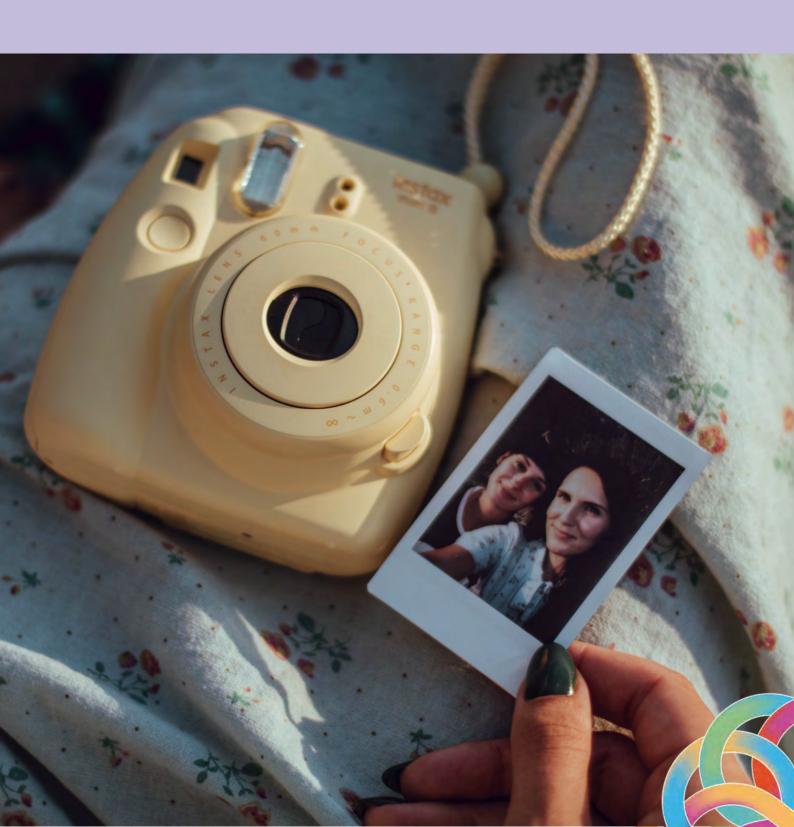
* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Reflection

Take a moment to consider what your Autism 'looks' like. Now that you know you're Autistic are there some memories or experiences you've had that you can understand better?

If you like, you can note your thoughts on page 8 of the Workbook.



The benefits of a diagnosis

"After several sessions with a psychologist and a couple of chickening-outs, I finally plucked up the courage to stumble out the words 'I think I'm Autistic'. My psychologist responded, 'what would be the point of getting a diagnosis at YOUR age?'

I didn't return. I instead took her words literally (as Autistic brains do) and went on an exploration of the benefits of getting an Autism diagnosis at age 40.

Here's what I found:

- It got me into the NDIS (Australia's funding scheme for disability supports), including getting funding to see neurodiversity*-friendly therapists.
- It helped me to understand who I am, why I am and how to look after myself better.
- It gave me permission to do things that the neurotypical* world had told me to stop doing.
- I could explain better to people like employers why I needed things done

differently to others.

- I gained the confidence to hang out in Autistic and neurodivergent* groups.
- Coming out as Autistic on social media meant I suddenly attracted other neurodivergent people to me.
- I went on a mind-bending journey, revisiting my past and looking at confusing/upsetting incidents through a new lens. My Autism and people's ableism* explained almost everything that had gone wrong/weird in my life. I found a peace in this and in who I am.

So yeah, getting a diagnosis has been EVERYTHING for me. What's been your experience?

I acknowledge my privilege in being able to access a diagnosis. I believe that many of these benefits can and should come from self-identification or an exploration of identity with a skilled therapist."

- Charlie Park



If you are questioning your Autistic identity, or feel unsure about your Autistic identity, you might like to see some more information on Reframing Autism's '<u>lam questioning my identity</u>' page.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Diagnosis brings better language and understanding

"For me, my Autism diagnosis means:

- It's normal to feel mixed emotions about the diagnosis.
- It was such a relief and explained my whole life - why I had always felt different, why life felt like a constant struggle. There are continual 'aha moments' where I look back and realise how Autism was present in my life, I just didn't have a name for it.
- Having the language and research base to explain your experiences is validating. For example, getting headaches from perfume or the heat and sun, not liking tight clothing, experiencing sensory sensitivities, and challenges with executive functioning, such as finding it difficult to make decisions or complete boring or difficult tasks.
- My self-esteem is higher since understanding my diagnosis. I'm not defective, it's not because I'm not trying hard enough but because I'm wired differently and am expected to function in a world designed for the neuromajority*. It's validating to know that it's not just me, but that there are many others like me who experience life similarly. And there's a name to describe and explain my profile of strengths, challenges and differences.
- You're still the same you, you now just have a name to describe your life and experiences. Knowing you're autistic empowers you to accept yourself, self-advocate, have self-compassion because you understand your strengths and limitations."
- Jenny Mitchell

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Diagnosis brings self-understanding



"Before I discovered my Autism, I felt confused, on the 'outer' and struggled in social situations – even within my own family. I found many people struggled to believe me, as they would say they didn't think I was Autistic, usually because of social stereotypes. Many of us know those to some degree.

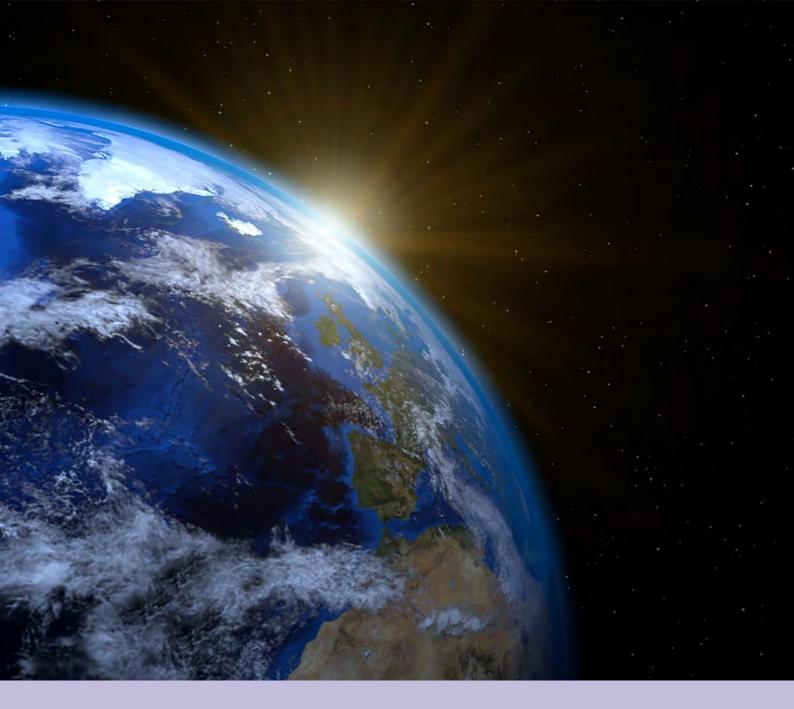
If we're quiet or withdrawn on occasion people may not understand why and jump to conclusions about us. I tend to be compassionate and allow for my emotions. I tend to cry a lot and often without an obvious cause. Expressing emotions for me is both tiring and liberating. I know that there is a lot we hold onto. I do feel having mental health support is vital. I also tap into our community's supports and networks some days when I get overwhelmed. My

support worker is great for recognising this as she and I are similar -she has ADHD. Reach out when you need to and get advice and support from friends and family.

When it comes right down to it, I have accepted that I do cry and am emotionally sensitive. I don't like loud noises and do shut down sometimes. But these are experiences I accept and can manage. There is no reason to feel shame or guilt, I see these things as just part of my lived experience and I take the good, with the occasional bad, but in all I am in a good place."

- Stormy Meiying Liu





You have so many strengths –strengths that come from being Autistic. The world needs people like you, Virginia. The world needs Autistic people.

- Ginny Grant, citing the clinician who conducted her Autism diagnosis





Diagnosis helps build a 'good life'

"I feel it's blending my Autism with who I am. And it's discovering in reflection how before I had known of my Autism, how well I had managed. Even with the challenges and struggles I suffered, not to mention my compensations, such as my blindness, my activism and fierce independence.

I feel I've learned much and acquired transferable skills and strategies.

These have always been present, but now I can more readily adjust and understand from when I had been unaware of my Autism and yet, how well I got through life until recent times.

Discovering my Autism has made a huge difference to living a good Autistic life."

- Stormy Meiying Liu





It is an uncanny thing to view your life through an entirely new lens, and that of a neurological developmental difference. Although it has been confronting to return to some of those memories, I can finally make more sense of them, fit them into neater boxes...

- Ginny Grant



Reflection

Take a moment to consider your discovery that you are Autistic. How has your new understanding helped you to make sense of your past?

If you like, you can note your thoughts on page 9 of the Workbook.





Some possible strategies to process an Autism diagnosis

- Having time alone in a familiar, controllable environment without any distractions to read lots of resources and to think.
 - Finding Autistic advocates to follow on social media through #ActuallyAutistic, reading their posts and watching their videos.
 - Reading books written by Autistic adults.
 - Doing exercise classes.
 - Spending time with other Autistic people (maybe finding a group for Autistic adults). Learning about your new identity and processing things by talking to them.
 - Writing or talking about your experiences of diagnosis publicly by creating a blog, podcast or social media account, publishing an article, or being interviewed by media.
 - Getting professional support from a therapist.
 Autistic adults may not want to go to mental health services because they had prior traumatic experiences there. In addition many Autistic people find traditional talk therapies and Cognitive Behaviour Therapy unhelpful and distressing for them.
 - Autistic adults may feel comfortable seeing a therapist in a private clinic, especially one who has lived experience of neurodivergence*, and practices alternative therapies such as Art Therapy and Animal Therapy.
 - ~ Charlie Park

For some other strategies, you might like to see this <u>article</u> on navigating a new diagnosis.

* For a definition of terms, see the handy glossary on the Reframing Autism website here:

https://reframingautism.org.au/service/glossary-terms/



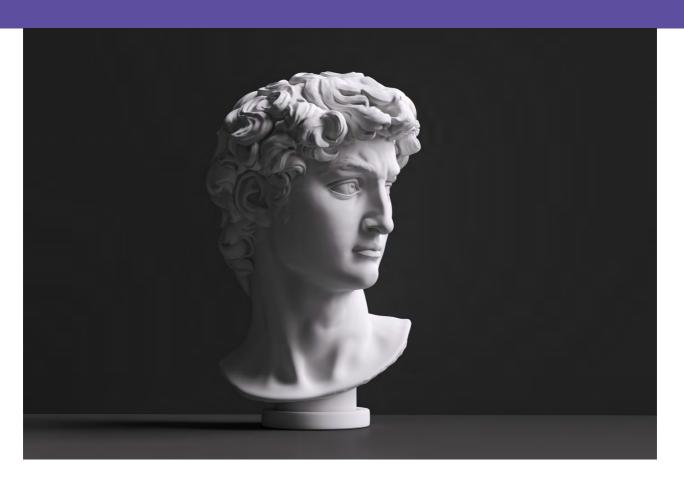


With a new Autism identity, there can be a lot of new information, trauma and/or grief to process.

There's no right or wrong way to feel, how long to take or way to do this processing.

Most Autistic people take time – months or years – to work through it.

- Charlie Park



The importance of understanding and information in the early days

"When I first discovered I was Autistic, I feel I would have benefited from having supports, especially to deal with those who did not understand my Autism and had made my life unpleasant. There are always situations that challenge us, and not everybody – including friends – cross our paths with understanding. Sometimes people can be downright aggressive.

Those were rare occasions, due to the projections of others simply not understanding. A former bestie did this to me, and it was a toxic ending to the friendship. It did take some time to rebuild my self-confidence. Learning more about my Autism and ND* made the world of difference. I have a great psychologist as well.

There are various ways our unique circumstances can differ. Being blind, my communication style is often the subject of harsh judgements by those who privilege making eye-contact as part of their communication. For me, eye-contact is not an issue, as my blindness offers me a mask of sorts. On top of this, there was a lack of knowledge about Autism when I was a child.

Understanding and information is so important and can offer us the tools and the resources and help us be better prepared. Then we can share our lived experiences and knowledge. But above all, it helps us to hold our heads high and give life our best."

- Stormy Meiying Liu

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Reflection

Take a moment to consider what strategies might be helpful to you to support you to process your new knowledge about your identity.

If you like, you can note your thoughts on page 10 of the Workbook.





Navigating 'community' after diagnosis

You may also begin navigating what 'community' means to you, and for many newly diagnosed Autistic people, seeking out neurodivergent* communities can be very validating and affirming.

Depending on your unique needs, you might also choose to start seeking supports or finding accommodations that can help you thrive in your life.

If you are in Australia, it may be appropriate for you to consider your eligibility to access the National Disability Insurance Scheme (NDIS), which can provide funding to help pay for these supports.

Equally, though, you may wish to take your time to just 'hold space' for yourself and your new clarity about yourself. There's no rush to do anything right now, as you work through what your new knowledge means for and about you.

Each person's journey is unique to them, and there are no 'right" or 'wrong' ways to go about processing this new information.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Barriers to diagnosis

"Getting a diagnosis for Autism and neurodivergence* is costly and not so easily accessible for all.

Some conservative practices within the mental health and primary care fields have biases, and lag behind the latest information and research.

This means we often need to shop around as some in the field lack up-to-date information and contemporary research in the field.

There are always new things to discover, but the machinations of government policy, law and the NDIS can be somewhat overwhelming at first.

This is why advocacy and activism can be a valid path for those of us who wish to put up our hands and make a difference."

- Stormy Meiying Liu

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Self-identification can be enough

"Self-identification of Autism is not only valid but is sometimes better than formal diagnosis.

The DSM-5* Autistic diagnostic criteria were primarily designed to identify young children in distress and/or with behavioural and developmental problems.

The criteria were not designed to diagnose all Autistic folk and they didn't - they missed most Autistic girls/non-binary kids who tended to have fewer behavioural problems than Autistic boys, and Autism diagnosis favoured white kids too.

So what about the rest of the Autistic population - all of those undiagnosed Autistic children who've grown up? Do they need a formal, clinical diagnosis?

I think sometimes yes; to access government supports and to avoid

unnecessary psychiatric treatments from misdiagnosis of mental health issues. However, I don't think that a formal diagnosis is always necessary. There are huge waitlists and costs for formal diagnoses (we don't want to further overload diagnostic services). Plus it's hard to find clinicians with any knowledge of Autism in adulthood. Formal diagnosis is based on observation of the person and self-report anyway - something many Autistic adults can do for themselves.

When Autistic adults want to understand themselves better, to learn the best self-care for themselves and to find like-minded souls, self-identification can be enough.

The knowledge of and acceptance by the Autistic community is enough."

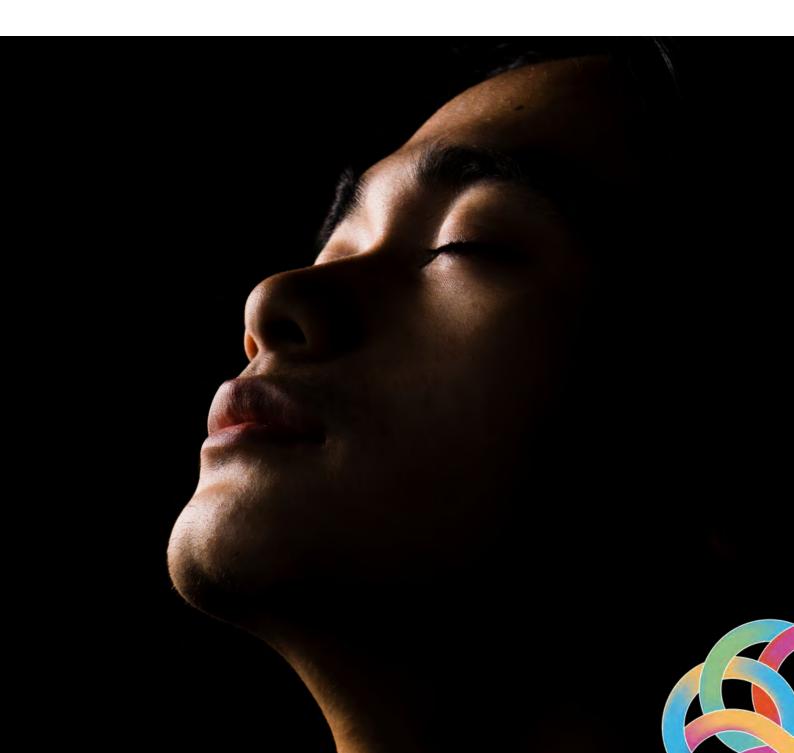
- Charlie Park

If you are questioning your Autistic identity, or are unsure about your self-diagnosis, you might like to read some articles on 'questioning your neurotype' and 'am I Autistic?'

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Part two: Autism acceptance, self-compassion and self-care





In Part two: Autism acceptance, self-compassion and self-care, we touch on the following:

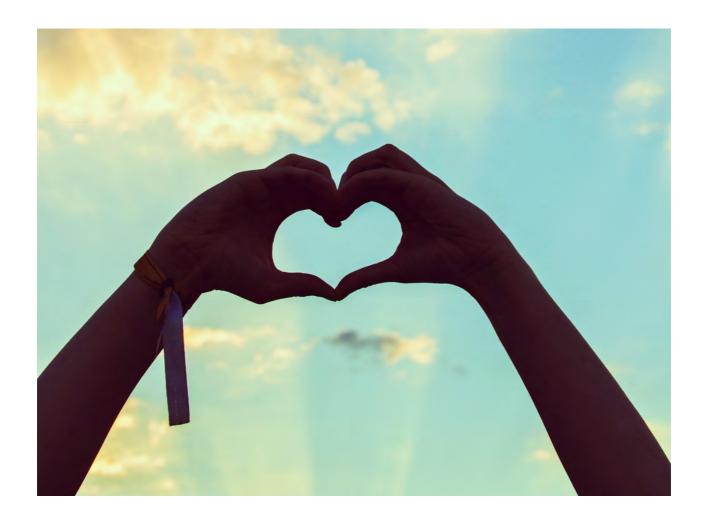
- Being worthy of love and respect,
- Finding self-acceptance through selfunderstanding,
- Acknowledging that experiencing self-compassion and self-acceptance can be a long and challenging process, that takes time and support,
- Some ways that self-acceptance might look different for each of us,
- The connection between selfacceptance and self-care,
- Some elements of Autistic self-care, including knowing your rights, asking for accommodations, and normalising needing support,
- Examples of our self-care, including self-care through self-love, selfrespect, asking for help, and selfacceptance, and
- How self-advocacy is a form of selfcare.





We acknowledge that many Autism journeys require self-acceptance and self-compassion, and wanted to share some of our thoughts on these here...





I am worthy of love and respect

"I think of all the people who have believed in me and **keep telling myself that I am worthy of love and respect**.

I remind myself of the successes I have achieved, including making it to Year 12 at mainstream school despite enormous attitudinal and structural barriers, graduating from university and doing post-grad studies, as well as doing work as an Autistic advocate.

When people dismiss, ignore or fail to acknowledge me, I do my best to look for alternative explanations of their behaviour, e.g., they're having a bad day, or don't understand our challenges, rather than internalising their deficit-based narratives in going straight to self-loathing."

- Tim and Sarah Chan



Self-understanding leads to self-compassion

"My upbringing was not conducive to self-acceptance nor self-compassion. It has nothing to do with my Autistic identity, but I can appreciate now how my neurotype* made it even harder for me growing up, because I was different.

When I was identified AuDHD* at 32 years old, it was revelatory for me and truly did validate my entire life experience.

For me, everything then fell into place, and it has made accepting myself and trying to

embrace self-compassion easier (not easy, just easier), because I now can appreciate that I am simply built a different way.

I am not lacking, I am not incompetent, or lazy, or unmotivated, or any other negative label. I am just different.
Once you understand that, you can accept it, draw on your strengths and get support where you need it."

- Sarah Climpson



* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



I accept myself unconditionally, embracing my idiosyncrasies, accepting my life's journey as part of my life; being gentle with myself and understanding and empathising with others, that is essential; shifting my previous outlook and with fresh eyes; discovering the depths within me as an Autistic woman opens-up so much more to explore.

- Stormy Meiying Liu





Self-compassion and selfacceptance aren't always easy

"It is a long, hard road to follow when you are searching for true selfacceptance and self-compassion. It is a path I walk daily, and I stumble and fall often.

I think the journey is particularly painful and difficult for adults who are late identified, rather than adults who have known their true identities their entire life.

This is because we have had decades of listening to negative internal and external narratives, potentially traumatic and challenging childhood experiences and significant mental health struggles as we have had to navigate a neurotypical* world whilst not fully understanding or appreciating that we are not neurotypical."

- Sarah Climpson

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Acceptance requires ongoing work, like addiction

"Fighting acceptance is like battling addiction. The analogy 'addiction' seems appropriate because unsubscribing from the stigmas around Autism is fighting against something that can feel all-consuming and inseparable.

Given the Autistic penchant to have

persistent and rigid thought cycles that can be addictive - addictive in the way being in misery is comforting to the extent that it's a place that provides some validation, while feeding like a parasite on the thoughts that are keeping you stuck."

- Alex Pilgrim



2. Acceptance 6:



Self-acceptance is a process

"Finding acceptance has a process with stages such as:

- **Recognising** you experience emotional distress and need help.
- Seeking help, this can start with simple conversations with people you value. If you feel you need it, approaching a healthcare professional for counseling could help you work through to accepting your diagnosis and sense of self.
- Tolerating the distress you feel towards yourself and the 'problem' e.g., internalised prejudices and societal stigma.
- Mourning and/or grieving your identity and sense of self that requires time to heal and rebuild.

- Relapsing in this context would be feeling overwhelmed by the 'lonely work' you need to do to accept your new diagnosis. This diagnosis isn't who you are; it's as big or small as you want it to be. The distress you feel towards this new knowledge will fade and you will heal. You are worthy of living a meaningful life.
- Accepting the final stages in rebuilding a person's identity and reclaiming a sense of self-worth.
- Feeling pride when you have reconciled with all you feel you may or may not have missed. Before you knew how to support yourself and understand what you need."
- Alex Pilgrim

Finding self-acceptance takes time and support



"As a newly identified Autistic, these three things are **essential for fostering compassion and self-acceptance**.

1. Understand that this process is a marathon, not a sprint. You are not going to wake up tomorrow and be enlightened. Self-compassion and self-acceptance are integral to wellbeing, but this is going to be a work in progress. Be prepared to do the hard work – you deserve it.

- 2. Get help. If you are privileged enough to access professional help, do so. You don't need to unpack your life and deal with your emotional obstacles alone.
- 3. Surround yourself with people who are compassionate towards you and accepting of you. It's helpful to adopt new practices when you have role models to show you how."
- Sarah Climpson



Finding self-acceptance takes time and support

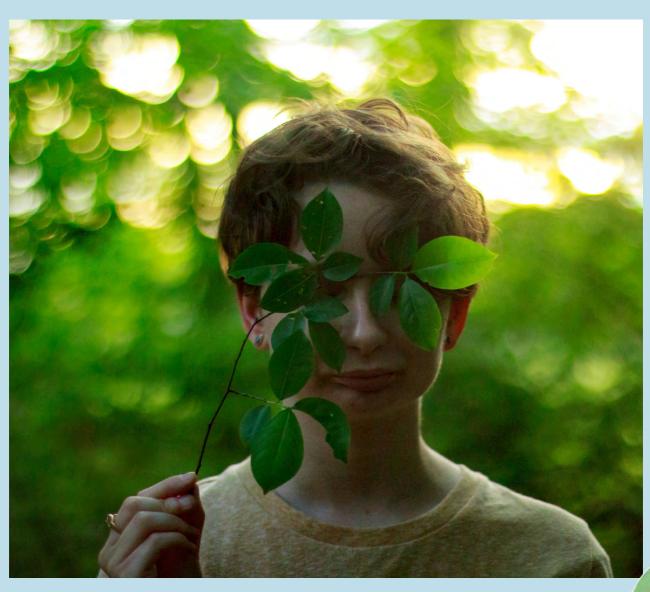
"I have engaged in psychology treatment for many, many years.

Several years ago, I was fortunate enough to find a practitioner who has helped me to unpack a lot of the trauma that I have experienced in my life.

This, combined with going through the formal assessment process and realising my true identity, has allowed me to be better placed to adopt a position of self-acceptance and compassion.

However, it is still a daily struggle."

- Sarah Climpson



For more information on self-acceptance and identity you might like to find out more by viewing this video on '<u>identity and self-acceptance</u>', or reading this blog on '<u>Autism, ableism</u> and self-acceptance'.



Self-acceptance and self-compassion look different for everyone: Jenny's story

"For me, Autism acceptance and self-compassion means:

- Celebrating my achievements even when no one else recognises what I see as an achievement, e.g., getting all the Christmas gifts done on Black Friday and independently making lots of decisions when choosing the gifts. These are achievements for me because I don't like crowds, dislike Christmas shopping and find decision making hard. I was proud of myself for having a plan to maximise the sales and successfully pulling it off. I listed gift ideas for each person and looked on likely relevant shop websites. That way when I got to the shops, I knew what gift options were in the price range I wanted to pay. So instead of wandering aimlessly between shops looking for gifts and getting stressed making decisions in the crowds, I targeted the items I'd already seen online and just went to those stores and straight out. I didn't bother stopping for lunch or the toilets, which would have crowds and queues, but waited till I got home, to make the trip as short as possible. Being aware of my sensory needs and executive functioning challenges enabled me to plan and act accordingly.
- Accepting it takes me longer to get things done because of the executive functioning challenges I face.
- Knowing what re-energises or regulates me and giving myself
 permission to do those things e.g., massage (deep-pressure
 proprioception*), sleep, watching a romantic comedy, writing, walks by the
 water, sipping prana chai and fudge at a café, washing my hair, wearing
 comfortable clothes, having a laugh with a friend, jigsaw puzzles, having a
 tidy, organised environment."
- Jenny Mitchell

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Self-acceptance and selfcompassion look different for everyone: Shazzy's thoughts

"For me, Autism acceptance and selfcompassion means:

- Realising that not everything in my past was my fault or in my control – building my self-compassion.
- Working with a ND* therapist on learning what self-compassion is.
- Finding opportunities to practice self-compassion and acceptance catching the triggers AND the glimmers.
- Learning about how mindfulness can assist us with self-compassion."
- Shazzy Tharby

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Reflection

Take a moment to consider how you might build your self-compassion and acceptance. You might also like to reflect on any barriers you might face in practicing self-compassion and self-acceptance.

If you like, you can note your thoughts on page 12 of the Workbook.



We acknowledge that the journey to self-acceptance needs self-care, and wanted to share some of our thoughts on this here...



Rights, accommodations and selfcare

"Informing and educating ourselves about rights and thinking about possible accommodations can help us to thrive. Accommodations may be formal or informal. They might be things we do for ourselves and boundaries we set to make our lives easier, or they could be things like formal workplace accommodations. Formal workplace accommodations may include:

- Asking to work from home or have flexible hours if your job permits.
- Working in a quiet area, away from noise and bright lights etc. which may disturb Autistic individuals in ways different to NT* individuals.
- Wearing comfortable clothing that does not cause sensory overwhelm.

These are just a few basic ideas that might help you in the workplace. It's important to remember that although you can ask and you have a right for accommodations, employers also have rights too.

More information can be found at the Disability and the workplace, Victorian Equal Opportunity and Human Rights Commission.

Further information about Disability rights can be found at the <u>Disability</u> <u>discrimination, Victorian Equal</u> <u>Opportunity and Human Rights</u> Commission."

- Natasha Siryj



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Normalise accommodating everyone's needs

"I have the right to have my differences respected and my needs accommodated FULL STOP. There's no need for me to show or prove that I deserve these things because they are human rights.

Not 'only people who use mobility equipment' rights. Not 'only people who look disabled' rights. Not even disability rights. Human rights.

If I'm sitting on the floor of the train, clearly unable to stand up, don't ... say 'l can't see your disability, you don't deserve a seat'. Be a decent human being and offer me a seat.

If I tell you that the music is too loud for me, don't ... ask what my diagnosis is. Just turn down the music.

If Chloe Hayden (Australian Neurodivergent Advocate) asks to use the Sensory Room at your concert, don't ... request to see her diagnostic paperwork. Just let her in.

Let's normalise enthusiastically accommodating everyone's needs without fuss, evidence or intrusive questions because it's the decent thing to do."

- Charlie Park



Self-care examples (everyone's self-care will look different)

Examples of Neurotypical* Self-Care

Examples of Autistic Self-Care

Keeping busy with lots of work.

Cancelling all work commitments.

Spending hours doing one or two favourite activities.

Going out to a party or nightclub.

Staying home and having quiet alone time with your pets for hours or days.

Treating yourself to an expensive dinner at a new restaurant.

Eating your Safe Foods every day, all week.

Giving yourself time off from doing housework.

Rearranging cupboards into pleasing visual arrangements, putting things back into their places or painting your walls bright colours.

Inviting family and friends to your house.

Lurking in the chat of your favourite online streamer or Discord group.

Going out to see a film at the cinema.

Rewatching your favourite movie over and over at home.

Buying new clothes.

Wearing your favourite outfit - that's 10 years old and super soft - for days.

-Charlie Park





Practicing selflove, self-respect and self-care

"Find out what services and supports are available to you. Be open and honest with your partner and loved ones. You will find they will need your support too.

Communication can lead to couples discussing all manner of topics that are based on your relationship and topics that may need a third party, to bridge these things, especially if your partner needs to know how to be a supportive part of the journey. You can make that important adjustment, together.

Practice self-love, self-respect, self-care, and embracing yourself.

You've come this far, and now you've found a new sense of self. The journey is your own, and you're part of a broader community.

If single, or a young person, dealing with issues of bullying, or having the supports at school and throughout your education, are important. Here, you can advocate for yourself with other supports, family, friends and peers who have your back and walk with you through these early stages, to offer that emotional and practical support in a complex and sometimes difficult world."

- Stormy Meiying Liu



Reflection

Take a moment to consider what self-care means for you. What does (or could) self-care look like when it's **your** way (rather than what you've been told self-care should be or should involve)?

If you like, you can note your thoughts on page 13 of the Workbook.



2. Acceptance 73



It's OK to need and ask for help

"When you're faced with a challenging situation, or feeling overwhelmed, understand it's okay and that we can seek the help of those around us to learn how to cope.

I feel if you can reach out to those around you that are close to you and share your experiences, share what you've learned yourself from experience and from the resources, reading, listening and engaging with the community and research is a good thing.

I've found this extremely useful and eyeopening learning about your Autism and how in the past you had struggled, and gotten by, knowing is liberating, as you have a better understanding of why, it is possible firstly to forgive yourself as you had no idea until you were diagnosed that you are Autistic, so cut yourself some slack, as understanding yourself and your Autism gives you a unique opportunity to re-discover and re-integrate the past and present and forge a new future. Be patient with yourself, allow for the unexpected. Accept those times when you don't feel great. It's okay if you want to turn off your phone and just read. It's okay to honour those negative feelings and discover ways to cope and mitigate these things.

We're human, emotional beings and part of embracing and adjusting to your new diagnosis is allowing for these situations. Don't be afraid to share with somebody prepared to listen. Listening is powerful and it's a skill everyone should embrace. We are part of society and while society must change, listening to our fellow neurotypicals* can assist us to adapt to their world. It's equally important we impress our needs upon them. It is a two-way street."

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

2. Acceptance 74



Autistic functioning fluctuates

"My functioning has varied across my lifetime and situations.

Sometimes I'm highly competent and confident, and other times I'm having a sudden meltdown in public over something seemingly minor.

As I've gotten older, I seem to be collecting chronic illnesses and becoming more disabled and needing more supports.

With this degree of variability in functioning, it doesn't make sense to pigeon-hole me as being 'high functioning'.

It's similar to non-Autistic people - could you say that anyone is 'high functioning' for life? What if a set of traumatic events befalls them and they struggle to cope? Will they still be 'high functioning'?"

- Charlie Park





Self-advocacy is important to self-care



66 Self-advocacy is the ability to communicate your needs effectively.

- Know you have rights
- Inform yourself
- Connect with others
- Consider what you need



- Natasha Siryj



2. Acceptance 76

Reflection

Take a moment to consider what your own unique needs are. You might like to consider how knowing that you are Autistic helps you to define your needs, or what resources might support you to meet your needs, or how you might advocate for your needs to be met in different contexts.

If you like, you can note your thoughts on page 14 of the Workbook.



Part three: Developing a positive Autistic identity





In Part three: Developing a positive Autistic identity, we touch on the following:

- Different elements that are important when fostering a positive Autistic identity, including taking a strengthsbased approach, authenticity, perseverance and finding people who will listen,
- The connection between positive identity and selfacceptance, including accepting our passions, quirks and stims*,
- Strategies for fostering a positive Autistic identity,
- Feeling pride in our identity, and
- Disability pride what is it, and how can disability be an identity?

* For a definition of terms, see the handy glossary on the Reframing Autism website here:

https://reframingautism.org.au/service/glossary-terms/



The importance of adopting a strengths-based approach

"We believe that the narratives of autism, especially for those with complex communication needs, are predominantly grounded in the medical model*, and propelled by a fear-based economy for cures and intervention to conform to neurotypical* standards.

With a neurodiversity* approach, adopted in the Welcome Pack, the change in focus from deficits to strengths and pride become the currency to drive understanding and acceptance. For newly diagnosed autistics and families, this change in focus is paramount to our autistic identity based on our unique gifts and different styles of functioning."

- Tim and Sarah Chan

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





The importance of authenticity

"A positive autistic identity means being able to be your true, authentic self in your entirety.

It means being accepting of you.
Embracing all the spiky parts of yourself along with all the others. Most importantly, a positive autistic identity means that you do not apologise for yourself or view your autistic traits as weaknesses or things which make you 'less than'.

I love wearing my autistic identity loud and proud; I certainly do not shy away from being open about my neurotype*, and what that means for me. I openly talk about the things I do very well at, and the things that I might need support with. I understand and accept that I have a responsibility, to thrive, to discuss my needs.

I also understand that those around me have an equal responsibility to take ownership of their role in inclusion and accessibility and take action. This two-way relationship between myself and the people around me is critical to maintaining my health and wellbeing. Fundamentally, I am proud of who I am, and I am accepting, and this is how I remain positive about my Autistic self."

- Sarah Climpson

You might like to explore more about authenticity in this article on 'flourishing authentically'.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Shaping identity through authenticity

"I am a playful and fun person. I don't need to be 'Miss Popularity', no way! If I start talking to birds in the carpark, or act a little differently, I find most people are kind and even laugh along with me when I hiccup loudly in the supermarket or get excited about the features leading into stores, like surfaces. I love getting excited about these, and I'm having fun and hurting nobody.

I can be discerning when I need to be, but whatever your quirks, it is an extension of our emotional landscape - something I see as a strength. Some people can be mean, but they're usually troubled or upset about something in their lives. For me, its water off a duck's back. It's just a part of who I am.

As a woman in my mid-sixties (though I don't look it, I've been told, and I am proud to say I don't always act it) I am astute and have a deep instinct for reading a situation. So being excitable, as I am on occasion, I wouldn't want to be anything other than myself."



Fostering a positive identity needs perseverance

"A positive identity comes from selfawareness, of my own challenges and associated needs, and in finding ways to understand some of the limiting ways most people view Autistics, especially, nonspeakers*, in predominantly negative terms.

Self-belief comes from acknowledging our own good qualities, especially the courage, integrity, perseverance to keep going in the face of exclusionary barriers.

While it is important to realise our own need to be socially acceptable, this is hard for autistic people - particularly nonspeakers - to be able to live up to social expectations.

Because I don't fit the mould, I have to work very hard at accepting myself, warts and all. It's a work in progress, but the support of my social network and my successes in achieving my goals, drive my ability to booster my self-worth."

- Tim and Sarah Chan



For more information about identity, and its relationship to self-acceptance, you might like to access this <u>video</u> on the subject.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

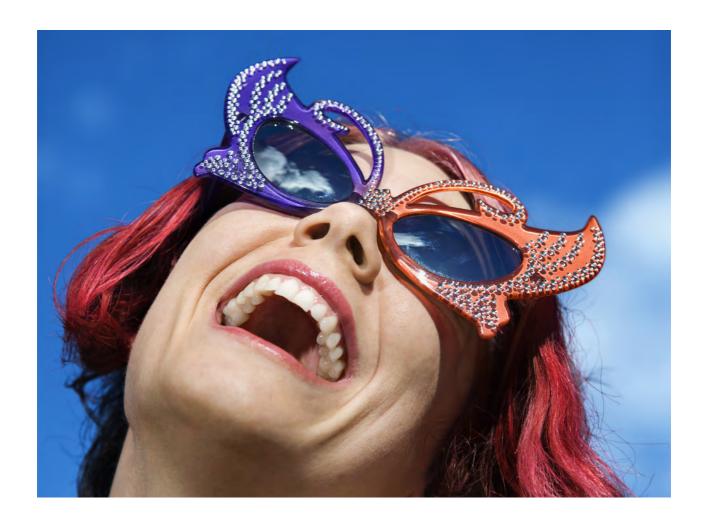
Finding people who will listen

"As people you love and interact with you are only just discovering your Autism, they need to know more. You can support them by letting them know more about Autism and ND*. Some may take time to come around, that's okay.

But those who do not, know that some people who find it hard to understand may not change - but that is their issue. It's like anything in life. We are drawn to people of all types because there is connection. It is a natural process, and those people who are willing to listen, learn and engage with us are pure gold."



* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Positive identity requires selfacceptance

"Fostering positive Autistic identity is accepting yourself and embracing that. Don't allow the pathologisation of Autism to get you down. We are wired differently and that, for me is a good thing.

And to be honest, I prefer to be as I am.

There is always something new and exciting I learn about myself.

Often, in fact, many of us, myself included, see our Autism as a wonderful opportunity

to be creative, beautiful, unique - and our unique talents give us the edge in many cases.

There are Autists who have been leaders in their chosen fields, in Maths, Science, the Arts and in public leadership roles. We have a lateral flexibility to think and act creatively and problem solve. We also have depths that I would encourage you to explore within yourself."





The importance of self-acceptance

"To me a positive Autistic identity means self-acceptance, and being proud of being Autistic, and allowing myself to shine, embracing my quirks, and making the emotional adjustments necessary.

I understand that some days I may feel I wish to be alone, not lonely, but simply enjoy me-time. A little solitude, also enjoying my quirks, being positive is to express myself on my terms.

For example, I love talking to birds, at home in my garden. Whilst out and about shopping I often will communicate with birds like ravens, crows, magpies and others.

I gain a lot of joy from this, and sometimes I act spontaneously, as my quirks are part of who I am."



Identity and passions



"Prior to diagnosis, a colleague tipped me off to my Autistic identity by pointing out how my eyes lit up whenever I talked about computer gaming. Having passions that are stronger and/or not typical for your age or gender is a common Autistic trait.

It's also common for Autistic adults to hide or dismiss these interests because they don't fit in with the 'norm' and can attract teasing.

Over the years, I've had many people tease me for being childish, nerdy or not

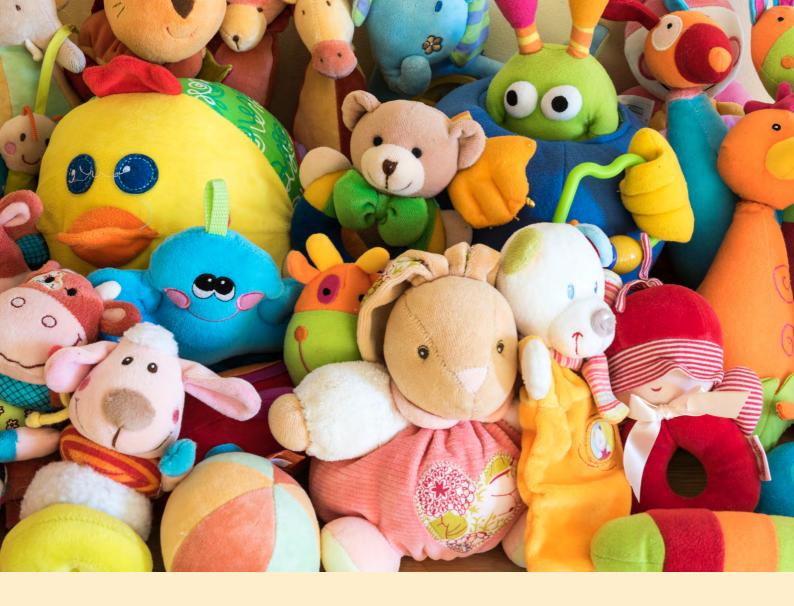
girly. I sadly let go of many interests to avoid teasing and try to fit in with neurotypical* expectations.

Since realising that I was Autistic, I've given a lot of thought to my lost and supressed interests. I've been working on indulging in these things –gaming, collecting figurines, vintage items, art and craft, writing, watching Star Wars and Marvel, wearing bright clothes.

I'm leaning into these eye sparkles and it makes me happy."

- Charlie Park

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Celebrating stims* and quirks

I stim* and fidget and have a MechaGodzilla Squishmallow. I love soft toys, and these allow me to release and express emotions and comfort, something that is important to me.

So you may have some of these quirks and ways of being and expressing yourself, those parts of you are yours, and ought to be celebrated.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Strategies for fostering a positive Autistic identity



"For me, a **positive Autistic identity** means:

- Knowing who I am and accepting that. It has helped to learn more about Autism and others' experiences, through podcasts, webinars, blogs, books.
 Knowing that I'm not alone in my experience.
- Writing helps me reflect on my life.
 Writing enables me to go back over my life and articulate how Autism was always part of my experience, I just didn't know it. Writing gives me a new lens through which to re-interpret my life. It enables me to understand what was happening, why I felt those things, why I responded how I did, why I

- experienced things like I did. I'm able to identify my sensory, social and executive functioning differences and how these impacted upon my experiences.
- Having a mentor, even if it means paying a professional. I regularly see a psychologist who - although is not an autism expert or neurodivergent* herself - is neuroaffirming*. It helps to have someone to share my concerns and questions with, a reflective mirror, someone I can run things by, check in with, ask for advice and see things from another perspective."
- Jenny Mitchell

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

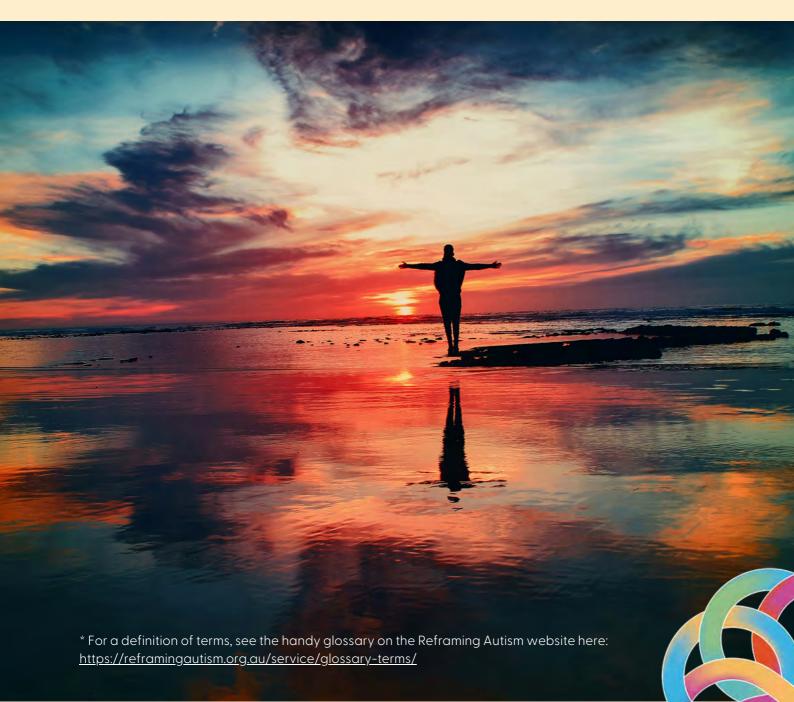
Strategies for fostering a positive Autistic identity

- "As a newly identified Autistic, these three things are essential for fostering a positive Autistic identity:
- 1. The key to creating a shift in this mindset is to start first with how you view yourself your identity is valid, your experiences are valid, you are valid. Reframing the way that we see ourselves as Autistic individuals is the first step. Take the time to reflect on who you are and what you bring and celebrate yourself for all you are.
- 2. Be prepared to challenge traditional social stereotypes of who and what Autistics are along the way!
- 3. Take care of yourself. Make sure you're looking after yourself and getting your needs met. You cannot shine if you're not feeling your best."
- Sarah Climpson



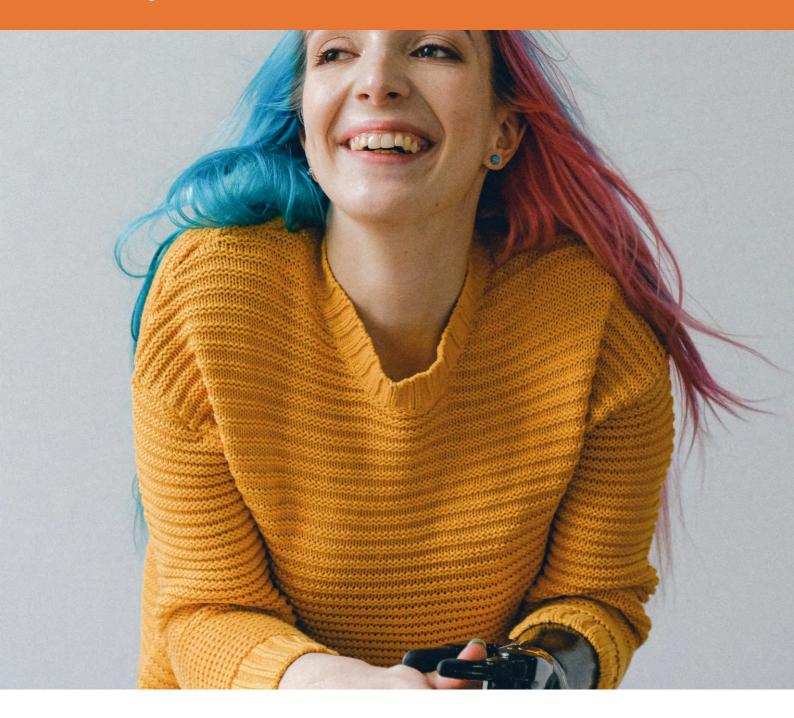
Feeling pride in our Autistic identity

- Being proud of who I am and also my autistic family (we are all neurodivergent*) means:
 - 1. Dealing with past trauma.
 - 2. Learning about autistic culture.
 - 3. Being your authentic-self/learning to drop the mask*.
 - Shazzy Tharby



For some of us, a fundamental part of our identity is in disability pride. Here are our thoughts on disability pride...





What is disability pride?

"A disability pride movement started in America is 1990 and has been joined by a more recent Neurodiversity* Pride movement. These movements have gained strength from the LGBTQIA+ Pride movement.

The movement is not about hiding or masking disability, but rather accepting

life is different without feeling less value.

One in five Australians has a disability.

While many face significant barriers in life, the right of disabled people are protected under the disability act: About Disability Rights, Australian Human Rights
Commission."

- Natasha Siryj

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Disability as an identity

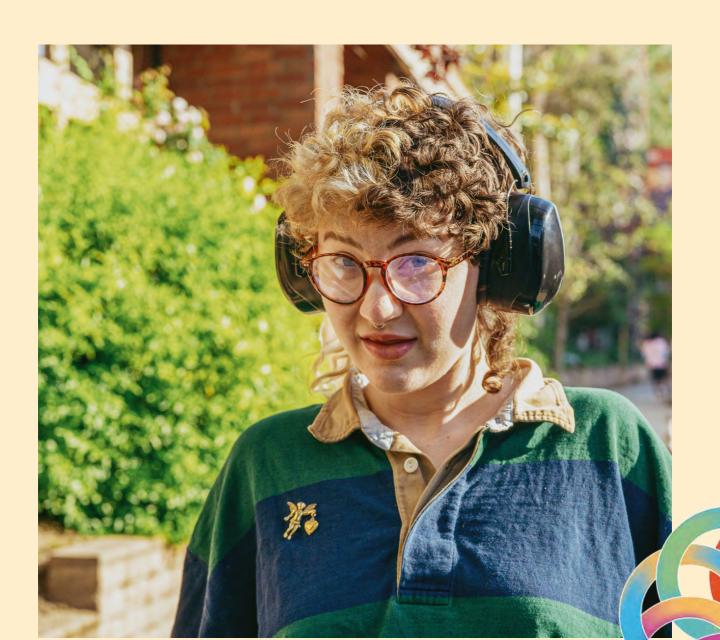
"Today, I realised why many people struggle with the concept of Disability Pride: they are focusing too narrowly on disability as only being an illness, impairment or difference in the body or mind. How could you possibly be proud of being sick?

However, for me, disability is an identity, a life experience, a political movement, a culture, a series of communities, and a disadvantaged group that's fighting for rights. There's much to be proud of here.

It's my new self-advocacy skills and disability advocacy work that makes me the most proud of who I am as a disabled person. How about you?

It could be: I'm proud that I'm still here, I'm proud that I went down the street with my mobility aid, I'm proud that I shared my knowledge to help someone else or I'm proud that I had the guts to try a new treatment."

- Charlie Park



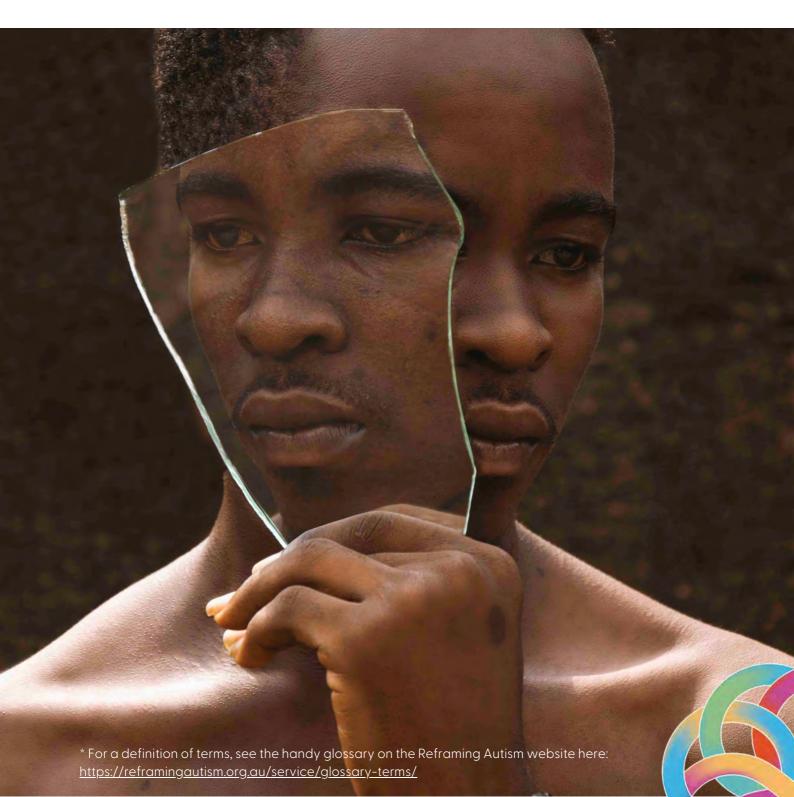
Reflection

Take a moment to consider what a positive Autistic identity means to you. Begin by thinking about the Autistic qualities of which you're most proud. You might find it helpful to begin by considering which of our stories might be something you would be proud of (because seeing strengths in others' Autistic qualities might be easier than identifying your own, and could be a first step to that!).

If you like, you can note your thoughts on page 16 of the Workbook.



Part four: Reducing masking* and camouflaging*





In Part four: Reducing masking* and camouflaging*, we touch on the following:

- Definition of Autistic masking and why we do it,
- What masking may look like,
- How masking may look different for non-speakers,
- How masking can impact wellbeing,
- Our experiences of reducing masking and unmasking,
- Strategies for reducing masking, and
- Imposter syndrome.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



What is masking* and why do we mask?

Autistic masking is something that most Autistic people (especially those of us who are late diagnosed) have learned to do to survive in the world. In some ways, everybody masks, or changes who they are slightly to meet the demands of different context (e.g., work versus socialising).

But Autistic masking is a much more intense – and often detrimental – process. Autistic masking is the (conscious and unconscious) suppression of your genuine self (including your Autistic traits) to be safe, conform, fit in and/or feel included in our environment.

Masking can take a huge toll on an Autistic person's wellbeing – mental, emotional and physical. As you learn more about your Autistic self, it's important to understand if and how you've been masking over the course of your life.

Understanding how masking has impacted you – and what you might have suppressed over time – will help you decide how you want to continue to live your life to embrace all your uniqueness.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



66 Masking* is a survival mechanism. It doesn't feel nice to mask. It feels unnatural, awkward and wrong.

Unfortunately, Western society and culture is not constructed to meet the needs of Autistics; masking therefore has become a necessity and more commonplace than not. 99

- Sarah Climpson





What masking* may look like

"Many Autists hide who they are, we camouflage* or mask*. This can be exhausting and takes a lot of energy. Masking can look different person to person but might include things like:

- Forcing eye contact
- Engaging in small talk
- Suppressing feelings and emotions, especially when heightened

- Hiding sensory overwhelm
- Acting differently to how we would normally act

We often mask as it is considered expected behaviour, it is the norm. Once we realise we are masking, it is possible to unmask*. Unmasking can be the first step for many of us to making changes and becoming stronger in our Autistic identity."

- Natasha Siryj

For some other experiences of masking, you might like to read the blogs on '#takethemaskoff' and 'finding my true self through the masks'.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Masking* may mean different things for non-speakers*



"For Autistic non-speakers, masking may mean different things, as we can't really mask our Autistic features such as lack of speech, or incessant use of rituals and stims* for self-regulating our constant overload and high anxiety levels.

But we also crave social acceptance and connection, and so we try very hard to fit in. But most of the time, these efforts can be costly in terms of refraining from self-regulatory behaviour such as trying to keep still instead of moving and weaving my body, or inhibit my natural impulse to vocalise.

In the long run, we have to remind ourselves that our needs, despite not being well-understood by most people, cannot be put aside without causing damage to our wellbeing.

Self-compassion means it is important to look after ourselves first rather than prioritising our acceptance by others in meeting social expectations."

- Tim and Sarah Chan

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



It is well known that masking* or camouflaging* can have a damaging impact on an Autistic person's wellbeing and contribute to Autistic burnout* and mental illness.

If you're interested in the research about masking, you might like to read this <u>summary of research</u> about Autistic adults' camouflaging experiences.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Reflection

Take a moment to note here the signs for you that might indicate you're masking*. If this is a new concept for you, it may take a while to get this understanding. How might that masking be impacting you and your wellbeing?

If you like, you can note your thoughts on page 18 of the Workbook.



^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



My experience of unmasking*: Finding a balance

"For me personally, unmasking means finding a balance where I can learn to express myself without masking* my traits. This can be difficult on occasion as I am not always aware I am doing it, but it does get easier.

I have a little quirk, when I get excited, I can do a little dance on the spot, and I won't try to tame that part of myself.

My bestie who has ADHD thinks it endearing and I love her for that as she accepts it, and it is something she embraces.

I do get excited, clapping and bouncing on my toes, and it bothers me not that I am 65 and acting like a teenager. So what? I love being me!"

- Stormy Meiying Liu

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.or g.au/service/glossary-terms/

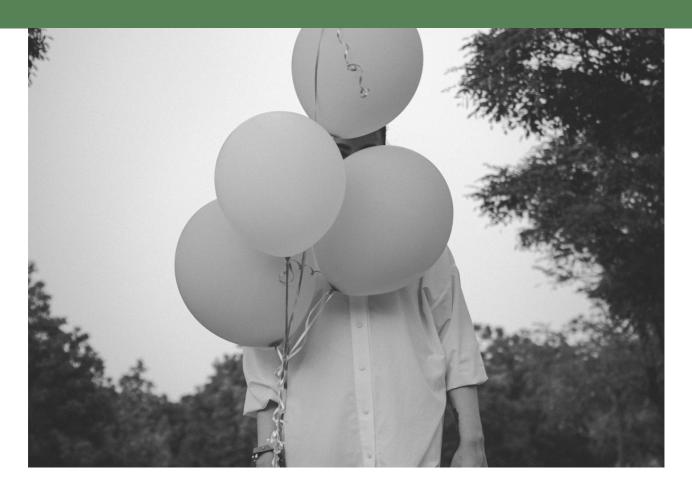




- 6 Reduced masking* has made my life more bearable. I've learned to be my authentic self through:
 - 1. Recognising masking.
 - 2. Understanding masking.
 - 3. Letting go of masking when it's safe for me to do so.
 - Shazzy Tharby

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





My experience of reducing masking*: The need for safety

"Reduced masking means an Autistic individual can experience their true authentic selves without having to hide, disguise or suppress any of their personality traits.

Reduced masking can only occur when an Autistic individual feels safe; in a safe environment and with safe people around them, and/or completely safe in themselves.

I have been masking my whole life and not ever realised, until I underwent my formal assessment; it was then that I began to understand that the ways that I acted and how they changed from situation to situation was all masking.

However, formal identification meant that I was then able to start to embody all the parts of my personality that might be deemed 'different' or 'quirky'. It's a work in progress, but the relief I felt, and weight that I felt lifted from my shoulders, when I was told about my neurotype* was marked.

I try to view all my traits as strengths that just need the right environment to be strengths in. It feels really good to be yourself, but it's not yet possible for me all the time."

- Sarah Climpson

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



My experience of reducing masking*: Acknowledging context

"For me, a reduced masking* means:

- At home with my parents growing up, I felt safe to have a meltdown and let everything out, be heard, share all my thoughts, ideas, fears and anxieties.
 Be accepted for who I am. My parents saw I had challenges and different behaviours but accepted that was who I was.
- In my marriage, I can be myself and feel comfortable.
- With my son, it is delightful. Both able to unmask* and have such fun together. Laughing and being silly.
 See so much of myself in him. I 'get' him. This helps me better understand what I went through growing up, which gives me insight into what might be triggering his responses, such as anxiety, uncertainty or overwhelm.
- In friendships, it is when others accept me as I am, are genuine, transparent and say things as they are. People who aren't fashionable or pretentious but are comfortable being themselves. Friends who have plenty to say and are happy to do the talking without expecting me to engage in small talk or carry the conversation. Often, I find it easier to connect with people from other cultures. There are already language and/or cultural differences, which makes my social communication differences less obvious.

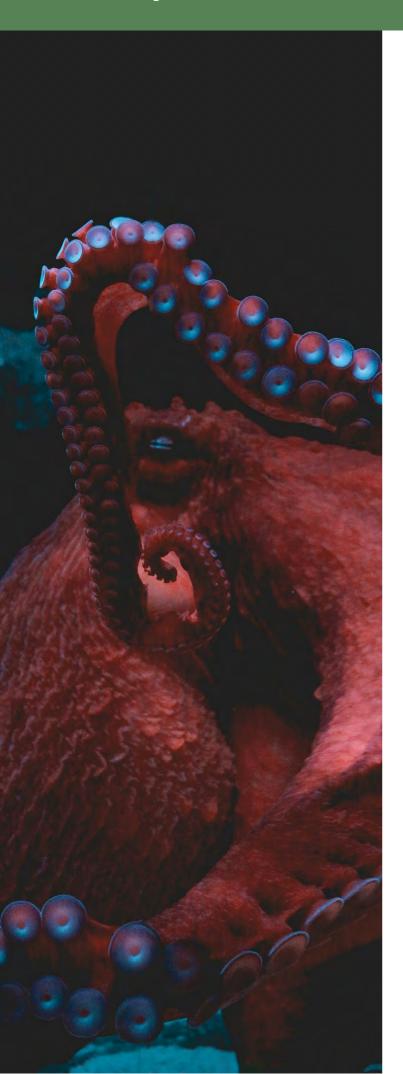
I've learnt not to feel guilty about my needs.

For myself, it is OK to need time alone. Not only have I come to acknowledge that whilst I enjoy company I crave and need 'me time,' I now also give myself permission to do this and self-advocate for that need. I've learnt not to feel guilty about my needs e.g. some days choosing to go to a quiet room to eat lunch alone rather than a busy staffroom, taking the evening to myself than engage with family when I'm tired, having some quiet time reading or writing at a café rather than coming straight home to tackle tasks. This helps to replenish and regulate me so I can then engage in the world again."

- Jenny Mitchell

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Deciding when to unmask

"It's popular to talk about 'Unmasking*
Autism' - throwing away attempts to act
neurotypical* and showing the world your
true authentic Autistic self. But in my
experience, this sometimes ends badly. Even
with some friends and even within some
disability spaces.

For example, I've been working hard on asking more clarifying questions when I don't understand something and speaking more freely. In response, I had a friend call me 'judgmental', other disabled people told me that I was asking them for too much information and a meeting Chairperson angrily shutdown my discussion. I've learnt that I need to be very selective with who /when I unmask vs camouflage*.

There is a very good reason why late diagnosed Autistic people like myself developed blending-in skills: to be safe. Rather than being an entirely bad thing, these coping skills were and continue to be useful. They are a form of self-protection and self-care.

I much prefer the term 'Autistic camouflaging' if not just because masks are creepy . 'Camouflaging' (like an octopus who changes colour to blend into the environment) fits my experience much better than 'masking'.

It is possible to practice both Autistic Pride AND Autistic Camouflaging. It is possible to be an authentic Autistic person who uses Autistic Camouflaging when needed."

- Charlie Park
- * For a definition of terms, see the handy glossary on the Reframing Autism website here:

 https://reframingautism.org.au/servic_e/glossary-terms/



Strategies for reducing masking*

"As a newly identified Autistic, these three things are essential for fostering reduced masking:

- 1. Reframe how you view yourself and your autistic identity. Acceptance of self is key to reducing masking.
- 2. Find safe places and safe people to start your unmasking* journey around. As you become more comfortable being yourself in familiar places, you'll feel more confident being yourself everywhere.
- 3. It's hard unmasking and being vulnerable. Make sure that you engage in acts of self-care and things that contribute towards a positive sense of wellbeing, so that you can fill your cup."

- Sarah Climpson



^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Reflection

Take a moment to consider reducing masking*. When might it be safe for you to explore unmasking*? With what people in your life could you explore unmasking with?

If you like, you can note your thoughts on page 19 of the Workbook.



^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Don't feel guilty for being yourself



"It is difficult for many of us to just be ourselves. Developing strategies, like being honest and presenting a positive attitude, must be [right for] you - [that is,] who you are away from situations that in the past were difficult. I am still working on this for myself.

Don't feel guilty for being yourself. Trust and feeling accepted has to come with the willingness of others to embrace you and for you in turn to embrace yourself. There are groups and resources in the community that can help with reducing masking* at work, and in social situations, I am more likely to test the waters and let down my guard, as masking tires me.

Don't be afraid to be as natural in these situations as is possible, but these things take a little time."

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Sometimes masking* can be necessary

"I hadn't heard of the term 'reduced masking*' before. I'd only heard of masking like wearing a camouflage to conceal to non-neurominorities* about my Autistic diagnosis. I was diagnosed late in my twenties. **Unlearning lifetime habits takes time and work**.

I do mask, perhaps in a reduced capacity. When I catch myself masking, I often flagellate myself for having 'Autistic moments'. I don't consider it to be an entirely negative phenomenon. It's moreor-less speaking a different language where most exchanges I interpret literally.

When I misunderstand others, I can feel silly for responding to implied meaning questions that don't require an answer. For instance, when a person asks, 'how are you?' it's usually a greeting and recognition. I almost always answer earnestly then feel silly. I'm probably masking to a degree, but it doesn't tend to affect my self-worth or identity.

What does affect me is not being able to mask in situations when I am tired and honest to a fault. This personality trait has affected my ability to navigate workplace relationships and sometimes in my personal life.

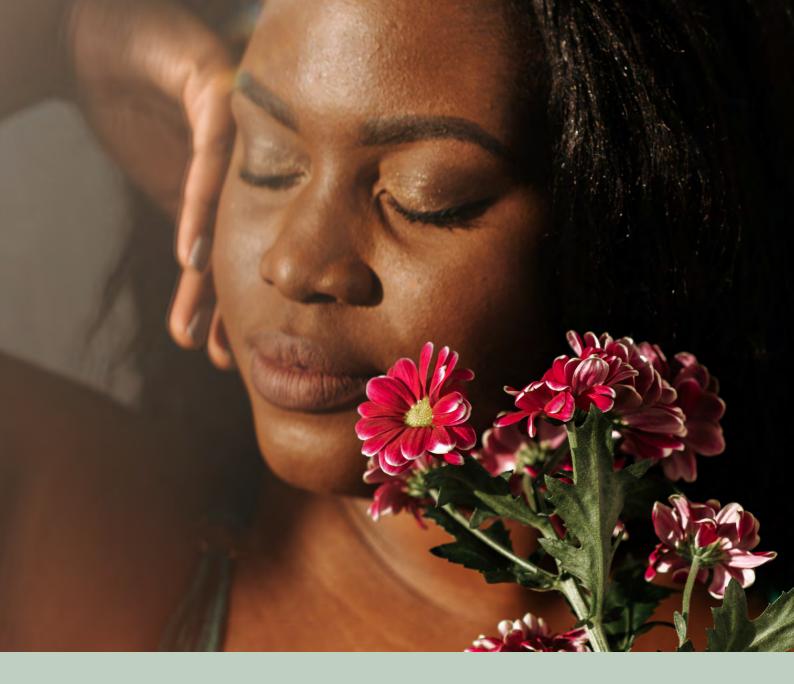
Autists aren't likely the only people to have difficulty in this area. Masking to some degree doesn't feel great overall. In some circumstances it's necessary to get by. I accept this social communication construct I don't have control over. On the other hand, unintentionally I'm practicing honesty which is a personal core value.

I recommend connecting with peers in a social context with supports where necessary. Learning about Autism may help on your journey to build strategies for everyday life."

- Alex Pilgrim



^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



• Please be gentle and kind to yourself. Be aware of your masking*.

For me, deciding to tell and explain my Autism is especially useful.

Learning to express yourself and your positivity about your Autism, is a good start. Baby steps.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Masking* and imposter syndrome*



So-called imposter syndrome is something most newly (and not-so-newly!) identified Autistics experience at some point or other. It's that feeling when you wonder if you really are Autistic, or if you're 'Autistic enough', or you question if the diagnostician made a mistake in diagnosing you. You might fear being called a fraud or being exposed as not really Autistic at all.

For many of us, we experience imposter syndrome when we compare ourselves to other Autistics (remind yourself, we're all different, and experience our Autism differently), when we are struggling with internalised ableism* and stigma (this might be because we feel we're inherently

broken and think that Autism can't explain our brokenness, or we don't deserve to have the diagnosis), or when we've masked for so long, and so deeply, that we're finding it hard to find our authentic Autistic selves.

Whenever you feel imposter syndrome, remember this: you're not alone! Very many of us have experienced the doubts, the worry, the persistent internalised fear that we'll be exposed as 'not really Autistic'. Also remember that you are Autistic enough just as you are — you don't need to 'prove' your Autism to anyone – and you are welcome as you are.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Reflection

Take a moment to consider whether there are times you feel more comfortable masking*? Can you be both authentic and true to yourself and also mask sometimes?

If you like, you can note your thoughts on page 20 of the Workbook.



^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Part five: Living a good Autistic life



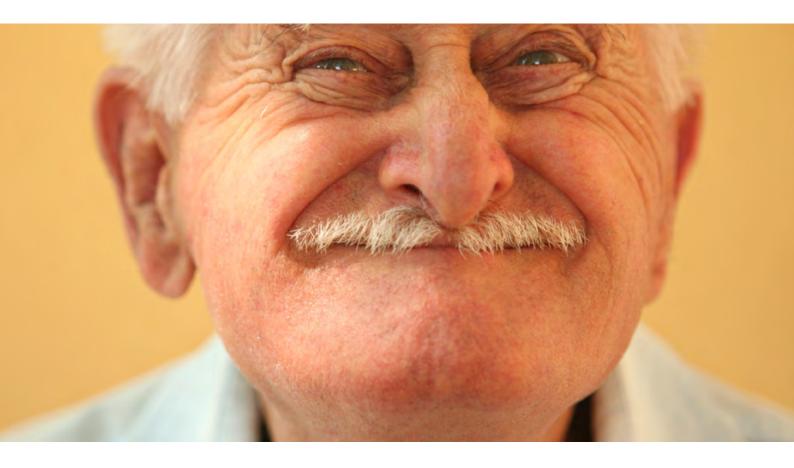


In Part five: Living a good Autistic life, we touch on the following:

- The key elements that help us to live a 'good life', including experiencing joy and meaning, embracing ourselves and our flaws, finding community and engagement, getting our 'kicks' and embracing our passions,
- The importance of authenticity to living 'good lives',
- The role of advocacy, the presumption of competence, and supports in living our 'good life',
- How thriving might look different for Autistics, and
- Some ways to foster flourishing and live well.



My good life: Contentment, joy, meaning



"My 'good life' means not apologising for being who I am and what I require to be healthy and feel contentment. But I prefer the term 'contentment' over 'happiness' because happiness is fleeting and temporary. I also prefer 'joy' over happiness as a descriptive term to describe happiness during meaningful experiences.

Language is powerful.

Especially when we consider our identities and our place in the world. A good life requires a sense of being able to feel we as people are worthy of all things that contribute to feeling joy.

On the subject of joy, I feel that creating opportunities to experience meaningful moments and experiences make life worth living. I consider meaningful moments and experiences to be the things we immerse ourselves in that make us feel contentment and joy.

Things like spending time doing and being with those we love. Having meaning in our lives can also be fulfilling your dreams such as the desire to work in a place that values you."

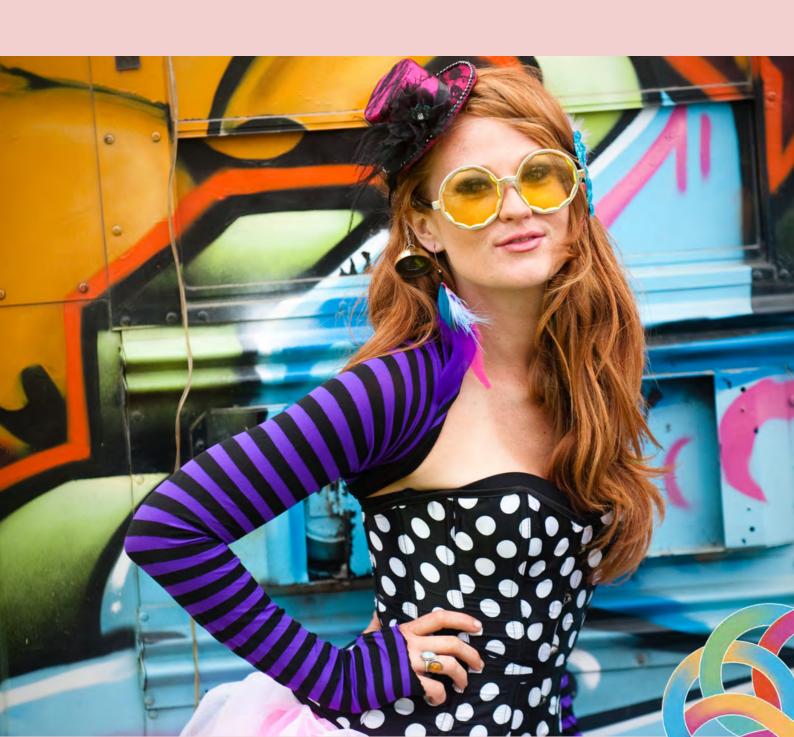
- Alex Pilgrim



6 Living a good Autistic life means being able to embrace yourself, love yourself and feel at peace with who you are.

It means being able to thrive in your environment, and being able to engage in the things that bring you joy, freely. It means being unashamedly you.

- Sarah Climpson



My good life: Being comfortable in my own skin



"Living a good life for me means integrating my life and my Autism into balance and being comfortable in my own skin. I have been fighting for myself, not only through activism within the disability movement but as a member of the LGBTIQA+ community.

When I came out, I made the changes

necessary to realise my desire to be wholly myself. My Autism and ND* have given me access to so much of the changes and experiences that continue now to inform my life.

I have found my place under the sun, if I can put it that way..."

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





My good life: Embracing the 'beautifully flawed'!

"My independence is important to me. Lifestyle and choices. Living alone has its benefits but I do wish to pursue a relationship. I am seeing somebody, and she too is ND* and likely on the spectrum.

I live by one prime directive, 'I am Beautifully Flawed'.

Balance requires I take the good and the bad, and when I stumble, this gives me the

raw emotional and mental materials to turn a negative into a positive. It means I can accept myself as perfection is a myth that I refuse to accept.

Everything is potential, and challenges can be tough, but they can also make us stronger."

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



My good life: Connecting and engaging

"Living a good life means how I can use my resources, inner and outer, to achieve my goals of living meaningfully. I find ways to feel good about life, to bridge this gap in meeting my goals in strategies to manage my Autistic challenges such as supported communication requiring facilitation, high anxiety levels, sensory, information processing and movement issues, etc.

Living meaningfully translates to connecting with people and engaging with the world, i.e., in my studies and my

advocacy work. To do this, I need to work hard to do better than expectations based on predominantly negative narratives of non-speaking* autism.

A good life would mean I can succeed in my tasks, develop skills and have good relationships, in the face of my challenges and functional limitations."

- Tim and Sarah Chan



* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



My good life: Getting my kicks

6 Hand-flapping is not a diagnostic criteria for Autism.

There are many other ways that Autistic adults get their kicks from repetition.

I'm particularly into whole body movements in space - swinging on a swing, yoga, hoop dancing, swing dancing, movement meditation. I spent all my playtime during early primary school on the monkey bars. I loved the whooshy high and I still do.

My good life: Embracing passions

"I have special interests, many of us do, and I honour these, as there is a wellspring of energy, creativity and emotional benefit from indulging in my passions.

My favourite is Godzilla. He represents the Earth Mother, a force for and of nature. He

is known as a Titan, and in the Godzilla universe and franchise, I love him and the other Titans, with a passion as I do the environment. I have all the recent blockbusters and documentaries and I do have figurines."





My good life: Being authentic to myself

"I consider myself a person before I consider myself disabled or Autistic. Living a 'good life' is being authentic to myself and living by my values and core beliefs.

However, my own self-limiting beliefs adversely impact my quality of life. What's more disabling is how other people think and communicate their limited understandings. This is more disabling than my own beliefs and attitude towards myself.

The limits of my abilities fluctuate daily. I refuse to apologise nor feel guilty about caring for myself. Selfcare is a requirement not an obligatory 'special need' that requires validation.

My quality of life includes practicing self-compassion and allowing myself to do what is necessary to be able to be a 'functional human'. Whatever that may really means is highly subjective and individual in nature."

- Alex Pilgrim

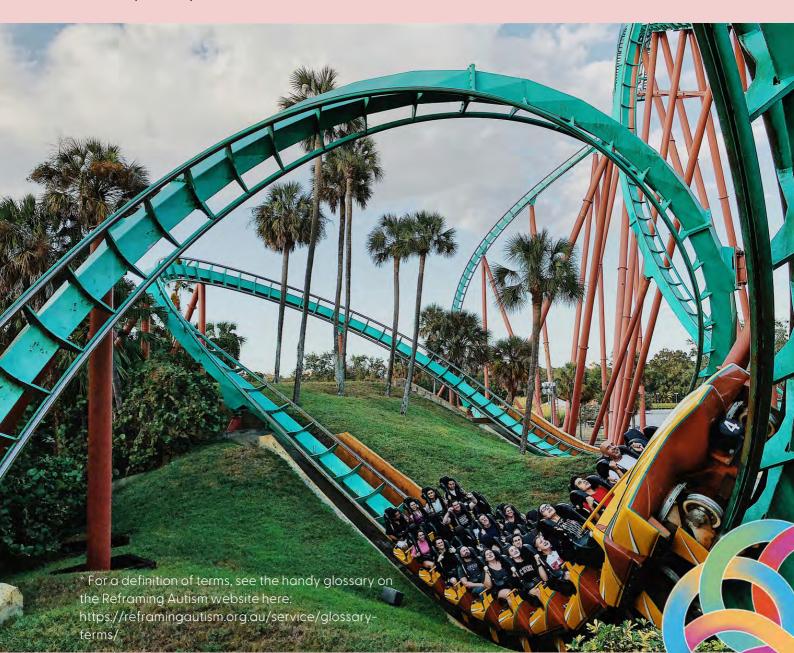


Tips for being authentic

Tips for being your authentic self and encouraging others to do the same:

- 1. Make sure any therapists you see are neuro-inclusive* and neuroaffirming*.
- 2. Realise that the journey from diagnosis isn't a train ride it's a rollercoaster.
- 3. Become knowledgeable about and open to various co-occurrences.

- Shazzy Tharby



The importance of community and supports

"As much as it is your journey, you also need to seek support from family, friends and loved ones where possible.

Remember, it is much of a journey for them as it is for you. Often you may have other Autistic siblings, parents and friends. It is therefore important to communicate with them. Some siblings or parents may hold back, others will be all-in and support you.

Community and the right supports can go a long way to mitigating misunderstandings and building bridges at home and work. That will be difficult for some, but there is support options in the community to help with dialogue and explaining your needs.

Self-advocacy skills can be developed also. Employers are a mixed bag, so seek as much support as you can."



The importance of advocacy, the presumption of competence, and a circle of support

"Living a good life means for people to presume our competence. We are worthy of a good life. We have the same rights. What we may lack sometimes are opportunities. Advocacy is essential. I can't emphasise enough the importance of self-advocacy.

I am sure you can work with your support circle on what is a good life and what you can do to bring it about. My life improved after I developed a circle of support. It is important to spend time developing networks.

There is a lot about Autism that we don't know. But we do know that it is diverse and what is a good support program for one person may not be right for another.

Some therapies are helpful. Speech therapy and talking to a psychologist have been helpful to me. You may find something else helpful. Learning is lifelong. Keep your expectations high. Life is good.

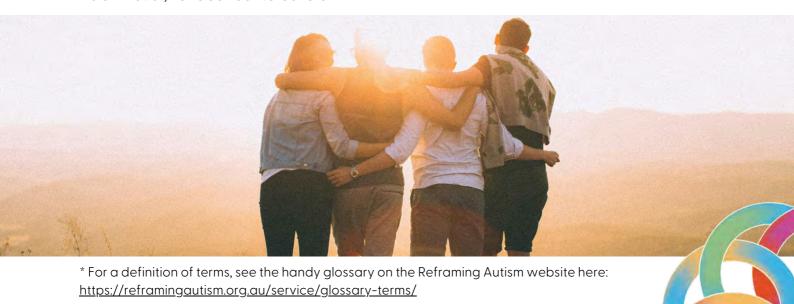
As an Autist, I endeayour to build a

positive self-image. My circle of support helps me in this. When I feel down, they help me to pick myself up. My long-term therapists have also been good here. Positive self-image takes work from myself and my supportive network from whom I pick up positive affirming messages.

It is not entirely our responsibility to build a positive self-image. Our environment has to support us by being positive and neuroaffirming*. Organisations like Reframing Autism that give us opportunities to work and use our experience to help others are important as well.

I have written about my life as an Autist in my book, **An Unspoken Story**. I feel that my life got better after I was published. Self-advocacy and a positive self-image are central to a good life."

- Hem (aka Sid) Chandran



Thriving looks different for Autistic individuals



"Fostering a sense of living well does not come easily for myself, as an AuDHD* woman and mother of two young neurodivergent* children. I believe that living well is linked to self-care, and finding time for appropriate self-care in a society which does not support Autistic individuals very well is challenging.

To live well, we need to have space to be, to exist. We need to have space and time to engage in the world in the ways which support us to thrive; this looks different for all Autistic individuals.

For myself, I need to be given time and space to do activities that support my

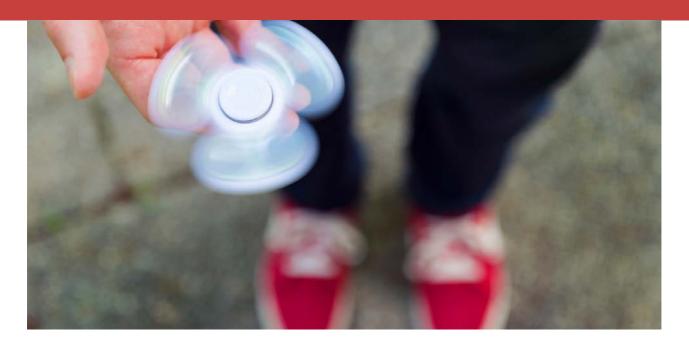
brain to 'defragment' or recover and reset. Time away from the beautiful chaos of my family helps (reduction in sensory overload), spending time outside on my property gardening and doing repetitive and predictable tasks is also very helpful.

Working also helps me feel accomplished and satisfied, as I am privileged to work in a role which offers me opportunity for my Autistic strengths to shine and flourish. I also need to be with people who support me and fully understand me; this removes any pressure to mask* or 'cope' when I am not otherwise able to."

- Sarah Climpson

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





How to foster living well as a newly diagnosed Autist:

- Do your best wherever you find yourself. Doing your best is being honest with yourself. It also allows you to 'hold space' and practice self-care whatever that looks like for you. Holding space means giving yourself permission to stop, take a breath and do what you need to do.
 - For example, giving yourself permission to 'stim*' even if it's uncomfortable to visibly self-regulate.
 If it's safe for you to do so. It's comforting to know everything is temporary even discomfort.
 - Create opportunities to experience joy, e.g., spend time on a passion project, commonly referred to as a 'special interest'. The term, special interest I consider perpetuating stigmatisation of the Autistic diagnosed person. Which implies a concept which can undermine an Autistic person's sense of pride in their identity.

- Give yourself permission to be who you are, do what you love and take up space to be exactly where you are.
 You are worthy of love, joy and living a meaningful life.
- Create opportunities to connect both in your comfort zone and outside it.
 Within reason and with support where necessary.
- If you are lacking direction and feel disheartened work to find what brings you joy and act on it, e.g., what have you always wanted to do or be?
- Make time to spend with people you love. If you find that challenging immerse yourself in something you love.
- Alex Pilgrim

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Essentials for living a good life

"As a newly identified Autistic, these three things are essential for being in a place to live a good life:

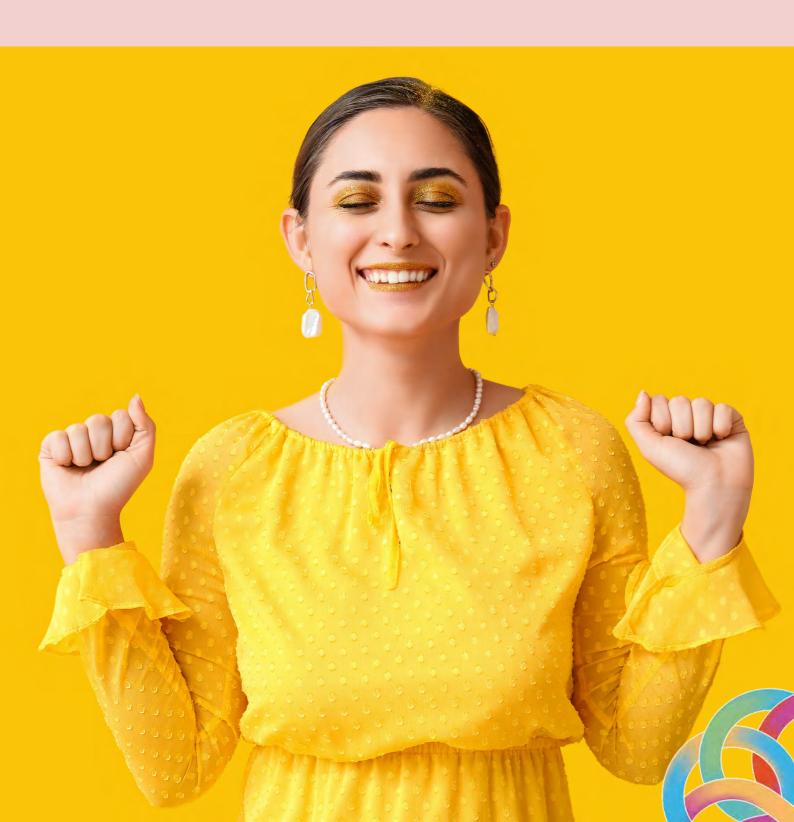
- 1. You will need to allow yourself the time to readjust and reframe your lens how you see yourself will change. Be prepared for this change, it is inevitable and it is necessary.
- 2. Surround yourself with people who love and accept you for your true, authentic self. There's no room for toxic relationships; you deserve to be yourself and know that you are enough.
- 3. Make time to engage in your deep interests. You know the things that fill your cup; your cup will empty fast, so making time to **do the thing that brings you joy and happiness is critical to avoiding burnout***."
- Sarah Climpson

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Reflection

Take a moment to consider what a living a good Autistic life means to you. Are there things in our stories that resonate for you too? What would **your** good life look like, and what steps might you take to lead your good Autistic life?

If you like, you can note your thoughts on page 22 of the Workbook.



Part six: What we wish we had known





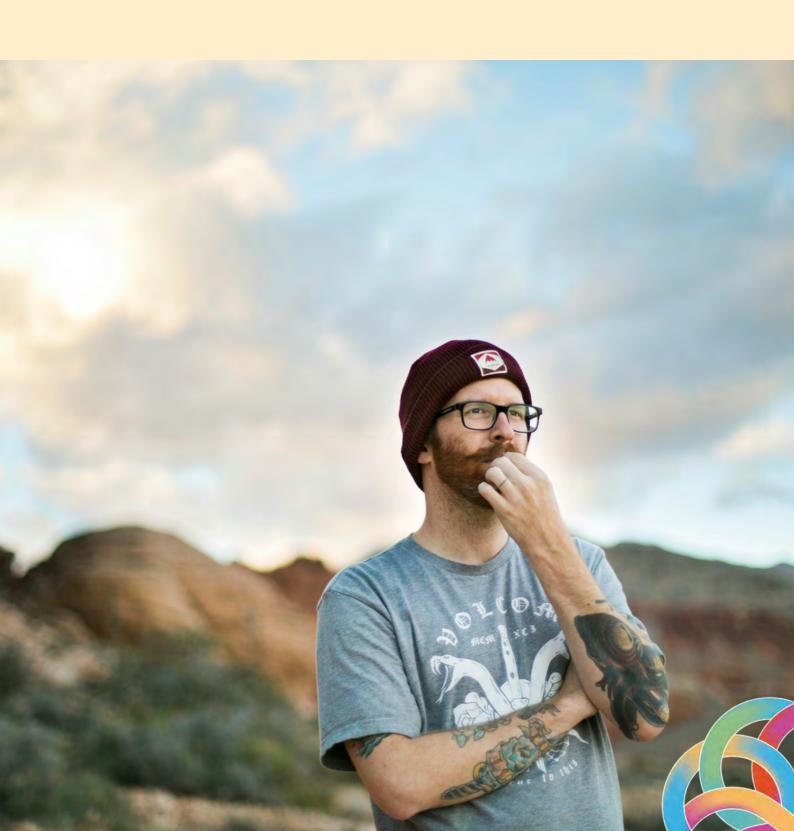
In Part six: What we wish we had known, we touch on the following:

- The importance of an early Autistic identity,
- Finding community,
- Our natural complexities,
- The importance of timely access to relevant information,
- Telling our stories,
- Our rights to be accepted and embraced.
- The importance of next steps,
- Tips to help you on the way.



In our own words, these are the things we wish we had known earlier, or when we first discovered we were Autistic.

As you read, do any resonate for you?





66 I think growing up Autistic and not knowing is very difficult.

Once you know and look back it's easier. The earlier the recognition the better the outcome.

Information needs to be targeted to Autistic young, Autistic youth, Autistic adults and Autistic elders.

- Shazzy Tharby



Finding community makes a huge positive impact



"For many Autistics it seems finding community makes a huge positive impact. Community can be found in many places. There are many online Facebook groups, local, national and international.

If you are on Facebook or other socials, you can try searching for Autistic groups and see what comes up. Sign up to mailouts and newsletters on these websites to gain information to your inbox and stay informed There are also in person meets. Check out websites for

Autistic based groups to find out more.

Through finding out more, Autism can become a special interest, an area where we do a deep dive to discover all the information! The more information we have, the more aware and educated we can become, and this can support us in self-advocacy and making changes.

Information can be empowering and gives us strength to be good self-advocates."

- Natasha Siryj

If you are interested in the importance of community for newly identified Autistic adults, you might like to read a <u>summary of research</u> done on this topic.

6. Wish We Had Known



We are complex and diverse

"It has been helpful for me to now understand why I struggled in social situations. Why I failed to make new friends and why people didn't get me. I struggled with failing to grasp context and then having made people upset with me.

Being blind didn't help. If other disabilities or being part of another community comes into play, there are deeper reasons to understand how these play a part in our

lives both before our Autism and after discovering we are Autistic and/or neurodivergent*.

We are complex and diverse. The rich tapestry of who we are, as well as our backgrounds, make for a more in-depth reflection and discussion – certainly for me as an Autist and neurodivergent individual."

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

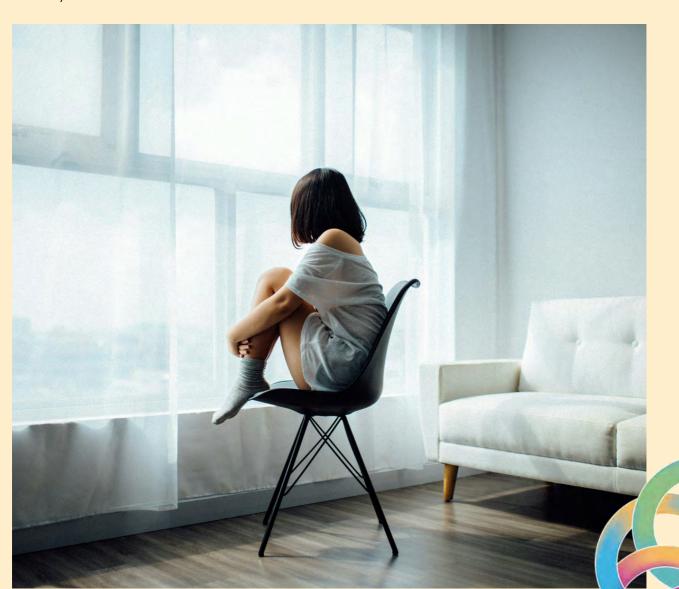


Timely access to relevant information

"My intersectionalities – adoption and anorexia - interplayed with my Autism. For example, repetitive physical activity which gave me proprioceptive input and elevated my heart rate, such as split jumps, tuck jumps, and skip hops, or stretching my muscles to their limit, all felt good. The problem was that these became obsessive because I wanted to continually replicate that good feeling. I became stuck in a rigid pattern which I felt compelled to do to feel good. Food became a special interest and something I could control when everything else in my life felt out of my control - including friendships and growing up.

Focusing on food and exercise and setting goals around these felt safe and achievable. I wish therapists had known I was Autistic, so they could have shown me other healthier ways to get that proprioceptive or interoceptive feedback. I wish I had been given help socially - help to talk through my anxiety and help to feel safe to grow up. I wish I was given strategies to manage my life so I could grow up confidently, rather than years of therapy focused on looking back at 'adoption issues' or trying to resolve 'anorexic symptoms'."

- Jenny Mitchell





Keep a journal: Tell your story

"Let me tell you, keeping a journal is amazing. As I write and re-write my life, and review, it is a living process of renewal - revisiting, evolving. It is a digital living memoir, a space I talk about all my passions, an extension of me and my journey of lived experience.

I encourage other Autists to 'tell your stories'.

Just as I share mine, I'd seek to give them the opportunity to express themselves, and their unique situations."



Reflection

You might like to think about beginning a journal. Perhaps you might like to reflect on the things that you are passionate about, and that bring you joy, contentment and engagement. Or perhaps you might like to start with capturing what makes you complex and unique. Or even just write a list of things you still wish you knew about your Autism.

If you like, you can use the space on page 24 of the Workbook to begin a journal.



We have a right to be accepted and embraced



"We have a right to be here, to live rich and full lives, to be accepted and embraced, to live in an inclusive society, and world. We have a voice. For me, my voice as an Autistic activist, Feminist, advocate, and writer, are but some of the things I champion in my life. We all have a place in this world and this life, and we want an inclusive reality for all.

I would ask of this world to reform and rebuild the education paradigm. Not only to rebuild but to expand and modernise it. To accommodate Autistic children and young people across our entire education system.

World-building is a skill we possess.

We can co-design an education system

that is based on a distribution of talent, of cross-pollination, where classrooms are restructured and can be integrated into all aspects of our towns, cities and institutions. Not based on a hierarchy that has done way more harm than good, but on a horizontal basis.

Making our children and young people struggle with a stubborn anachronistic education system is inhumane and fails to give our community the means to play an active role in making better world for us all. We can take those skills into all walks of life and occupations, from governance to business to politics and beyond. The sky is the limit!"

Don't be deterred

"In a classic case of monotropism*, my hypersensitivity issues mean that incoming information can be too intense. Managing these overwhelming sensory input places heavy demands on processing other incoming information.

So then, I find social events very taxing, with the additional need to take into account other people's perspectives, and social niceties such as showing interest and responding appropriately, in addition to working out what to say and typing it.

Furthermore, the ways in which we manage our differences may be unacceptable. For instance, whenever I experience sensory overload, I often need to put my hands on my ears, close my eyes, hum, or lie down.

People react to my weirdness, I'm seen as beyond the pale, and the barriers of exclusion pop up. So with our sensory and other autistic challenges, it is difficult to live up to social expectations of appropriate behaviour, and we face people's disapproval of our differences.

Let's look at a social event in which I was able to participate. In April 2019, I was invited to give a speech on world autism awareness day, at an event for stakeholders run by the Autism CRC in Brisbane. Although I was in a different city in an unfamiliar venue, I spent a lot of effort in preparing the speech as well as in psyching myself up for presenting in front of an audience comprising many notables in autism research and advocacy. We arrived a day earlier and had a tour of the venue. Feeling relatively confident, I was able to give my speech without problems.

Encouraged by my success, I was feeling good about the positive reception and feedback about my speech and felt ready to tackle the Presentation Day seminar on the following day. Walking into the seminar hall, with 10 tables each sitting around 10 people, I was instantly overwhelmed by the sea of faces of unfamiliar people

To deal with my elevated anxiety and overload, I made my way to the side where I laid down on the floor and shut my eyes to calm a nervous system which had gone into overdrive.

The next thing I knew, someone kneeling beside me and using his cap to shade my eyes. It was Wenn Lawson, the well-known Autistic researcher and advocate, who would soon be giving his presentation.

Although we had not met face to face before, we had connected through email, and I also watched him on Facebook and YouTube, so his presence was comforting.

After self-regulating, with Wenn's thoughtful gesture, I was able to sit up, and began to take things in. Thereafter, with renewed self-assurance that things would be fine, I got up to sit at the table, as I was far from feeling disabled. I am forever grateful to Wenn for his provision of additional personal adjustment for me to join in.

My point is, we need to be prepared to meet our challenges without being overwhelmed by the enormity of the obstacles most likely encountered or try to conform to prevailing social standards.

Make all necessary preparations, and when faced with setbacks, don't be deterred, take a deep breath and keep believing in ourselves and that things will turn out well, as we've done our best.

With a positive outlook, our needs in appropriate environmental adjustments as well as support from other people will materialise, often unexpectedly, so that we would be able to overcome the limitations of our physiological challenges, to achieve our goals and to participate and contribute on an equitable basis."

- Tim and Sarah Chan

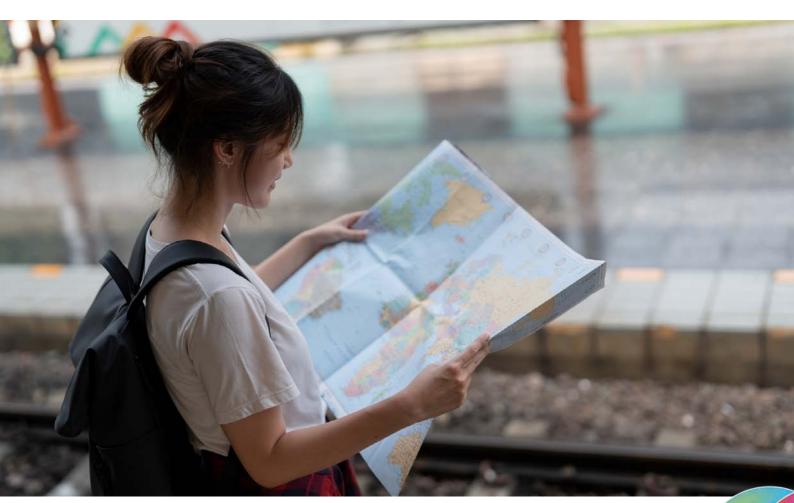
^{*} For a definition of this term, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Where to next?

"For me, I wish I had known:

- How and where to connect with other Autistics.
- Neuroaffirming* therapists for late diagnosed Autistics (lots out there for children or young adults 18–25yrs, but hard to find relevant resources for older adults).
- What next it's all very well to get the diagnosis, but it feels like there's very little support after that.
- How to explore common co-occurring diagnoses e.g., ADHD, sensory profile.

- How to get connected with another
 Autistic adult further along the
 journey who could mentor me through
 'where to next' in terms of accessing
 the NDIS, finding appropriate
 therapists, recommending resources
 such as helpful books, sites or
 podcasts.
- When, with whom and how to disclose, and the pros and cons of disclosure. Have other Autists developed scripts to aide disclosure?"
- Jenny Mitchell



If you share these questions, you might find it useful to visit the Reframing Autism page on '<u>lam</u> <u>newly diagnosed</u>', or the article on '<u>navigating being newly diagnosed</u>'.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Tips to help you on the way



I am an over communicator; I need to talk and explain things to the people around me so that I am understood and able to best be supported. I try and be as clear and transparent about what I need at any given time. This is really, really important for people who do not share my neurotype*; my husband, for example. It is a critical part of our relationship that I communicate clearly what my needs are, and where my head is at, and this helps him to know exactly how he can support me. The same is true for the relationships I have with my friends.

2. Rest:

This is impossible for me as a parent of young kids, but honestly it is exhausting existing in a world that is not designed for

Autistic folk, and the drain on your brain is multiplied compared to someone who is neurotypical*. Rest and recharge as much as you can, in the ways that you need. This helps to get through, avoid burn-out and remain regulated.

3. Find neurokin* and hold them close:

When you find your people, you will know it – don't let them go. The people whom you can be your authentic self around, who love you unconditionally and who make you feel safe and whole, these people you need to keep. Find them and keep them. They will help you survive in this world.

- Sarah Climpson

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Reflection

Take a moment to consider what you have read in this section. Which questions do you also have, and which pieces of advice might you would like to try in your own life? (The further resources on page 176 and the <u>Reframing Autism website</u> might have some answers to your questions, and help you to think about 'what next' for you!)

If you like, you can note your thoughts on page 25 of the Workbook.



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Part seven: What we want others to know





In Part seven: What we want others to know, we touch on the following:

- Debunking myths by correcting misinformation,
- Communication differences and strengths,
- Autistic social communication differences and empathy,
- Forming connections and relationships,
- Advocating for our needs,
- Supports and access needs, and
- Celebrating our strengths.



In our own words, these are the things we want others to know. As you read, do any resonate for you?



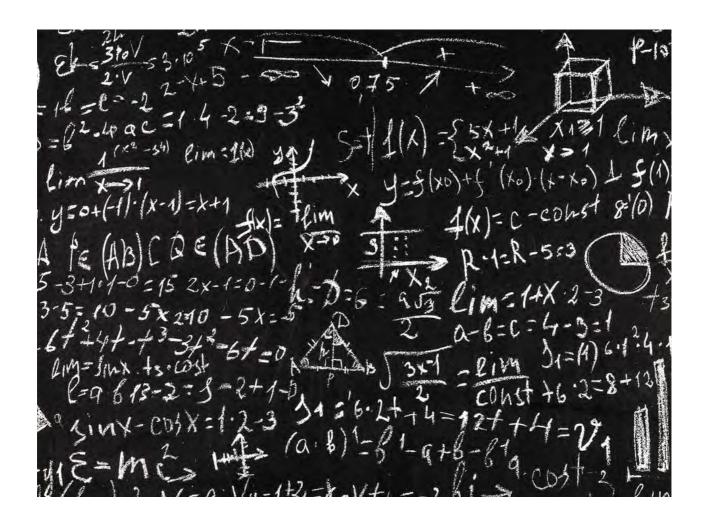


Myths, stigma, stereotypes and misinformation still surround Autism. We want to change that. We do not use the word 'disorder' to describe our Autism.

Instead, we talk about ourselves as different, not disordered, because Autism is not a disease or an illness, and it is not curable or treatable.

We want to change the lens so that society can see the strength in Autism, its value, and its beauty. On the Reframing Autism website there are a list of truths we want people to know. In the following pages, there are some more of our truths about Autism we wanted you (and others) to know...

7. Want Others to Know 150



Not all Autistic people are savants

The existence of savant syndrome itself is not a myth. It is a real thing. What is a myth is the assumption that ALL Autistic people have a savant skill. In fact, no more than 1 in 10 (or 10%) of Autistic people show some advanced level of a particular skill.

Even among those who do have a 'savant skill' the skills themselves are varied both in type and degree.

Autistic individuals often exhibit very specific and focused interest in a singular topic, sometimes to the exclusion of everything and anything else. This means they might have a higher-than-average level of knowledge on that specific subject.

Understandably, this might lead to confusion regarding whether they have savant abilities, but in reality, it is more likely than not simply an expression of their keen interest in the topic.

As you explore your Autistic identity, it doesn't make you 'more' or 'less' Autistic if you do (or don't!) have a savant skill. Even if some people around you assume you're not Autistic because you are not like 'Rain Man' or Shaun Murphy from 'The Good Doctor', that is ill informed. Not having a savant skill doesn't make you less valuable, worthy, or welcome. This is just another element of the rich diversity of our Autistic community.



Different understandings of Autism exist in different cultures

"I am afraid that stigma around autism exists mostly in my culture. In my case, slowly but not surely life has got to a point where I can disregard the most prejudicial elements of my culture. I have been making effort to build a support structure.

I am at a point in my life that I am surrounded by supportive and positive people who encourage me. I do not need to engage with people who are negative or who stigmatise people like me. I am making no excuses for them than ignorance.

An individual with a permanent disability is seen as a person not worthy of having the privileges of living in a family. I know people who feel that we deserve nothing more than food and shelter. We are seen as people with no rights.

Most people do not understand autism. They treat us Autistics as crazy people. They feel no need to pay any kind of attention to me and think that they can just treat me as I do not exist or ignore my presence if I am around.

Some people I have met are afraid that I might hurt them and physically distance themselves from me. The same people are gobsmacked when they see me type and use words.

I would like to make a list of the most harmful and disturbing beliefs and practices. But this will take time."

- Hem (aka Sid) Chandran



Our truths...

- Autistic communication looks different for different people. That means communication looks different between Autistic people too.
- Autistic people seek social connections and friendships, and may want (and have) romantic relationships.
- Autistic people have much to offer, but we often need to overcome many barriers to be able to thrive.



If you are interested in reading more about the Autistic need for connection, you might like this article explaining some research done on 'Autistic social motivation' and on the benefits of having Autistic connections. If you are looking for some information on romantic relationships, this <u>blog</u> and <u>video</u> might be useful to you.

In our own words, these are the things we wish others knew about Autistic communication...



Autistic communication differences

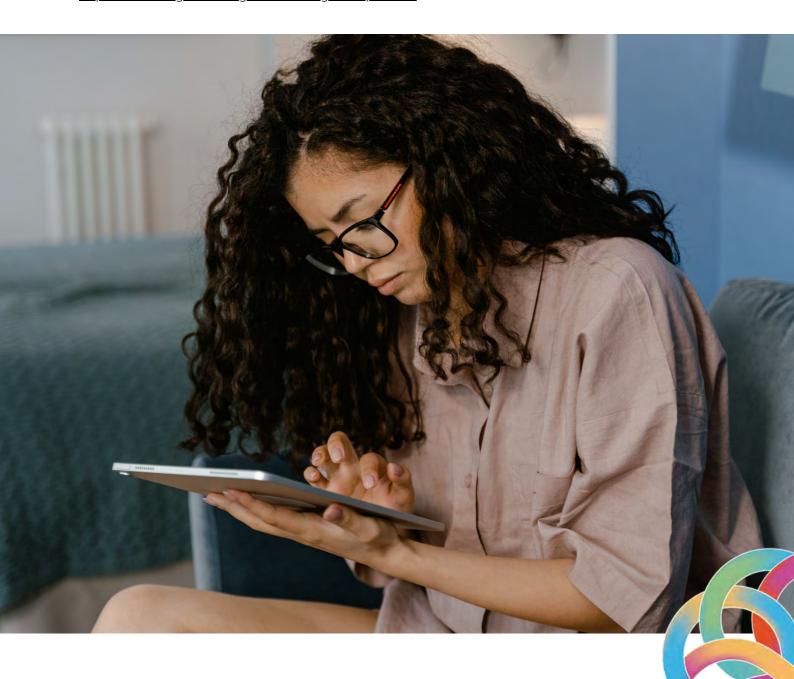
Communication differences are a core characteristic of Autism.

Whether we experience challenges in generating traditional speech and language or not, many Autistics use their strengths in visual thinking and auditory memory to communicate.

Approximately one third (33%) of Autistic individuals are non-speaking* (do not use speech) or minimally speaking (have unreliable speech), and require augmentative and alternative communication (Koegel, et.al., 2020).

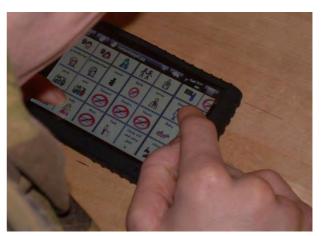
You might like to explore more about Autistic communication, and your rights, here.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



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In fact, Autistics use a range of communication strategies

Many Autists use multi-modal communication* and access a broad range of communication strategies to meet their context and needs across time. Recommended alternative and augmentative communication (AAC)* methods usually include Picture Exchange Communication System (PECS), language boards, alphanumeric keyboards and typing devices, and electronic symbol-and text-supported communication applications (like Proloquo2Go).

Approximately 25% of Autistics do not use speech at all to communicate (Wan et al., 2011).

Communication for these members of the Autistic community, often classified as people with complex communication support needs, may be non-conventional and diverse.

You might like to explore more about different types of Autistic communication here.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Autistic communication strengths



"You can't be Autistic if you can write a blog', posted a random mum of an Autistic child to me recently.

Just because I have a strength in written communication, doesn't stop me from being Autistic (it's actually a hallmark) or from having difficulties in other areas.

Writing gives me time to plan out visually what I want to say. Plus, I'm uninterrupted by a pesky communication partner. In contrast, I struggle with verbal chit-chat because it's hard for me to prepare my responses. This is all very Autistic.

My Autistic communication comes out with a formal/academic tone. I'm essentially the grown up 'little professor' Autism stereotype. I often sound more knowledgeable and confident than I am.

It's unsurprising that I have a large vocabulary because I read a lot of books during childhood. Reading was a special interest, calming activity and a retreat from social demands. I also hid from the workplace at Uni for many years - a place where my precision and academic tone were accepted."

- Charlie Park





An example of an Autistic communication difference

"Hospital staff have told me that I 'smile too much to be in pain'. I clearly need to practice pulling pained faces and doubling over in a performance of pain. 'Charlie! It's time to "do pain" for the doctor'.

A key feature of Autism is flat or fixed facial expressions and not using our bodies to express feelings in a neurotypical* way. So it's not surprising that I fail the 'are you in pain' test?

Add to that, I have lived with undiagnosed, improperly treated endometriosis and ME/CFS for decades. Maybe I've been habituated (gotten used) to pain and I'm too exhausted to put on a show.

I don't understand the concepts of 'whinging' or 'complaining' for sympathy. It wouldn't occur to me to do this. If I raise a concern, it's because I want a solution, I want something to change or I need a pain/stressor to go away, NOW please.

I also don't like wasting people's time and I don't like attention. So for me to go to a doctor and raise a health issue, it has to be really bad.

I want medical professionals to be aware that if I'm raising a concern then it's a big deal to me. I also want them to know that I have resting calm face; even if I look calm (maybe especially so because I'm dissociating from the pain), I can be in huge pain.

I'd like to see medical staff training changed to reflect the full diversity of pain presentations by patients, instead of just the neurotypical, non-disabled, healthy, white person's expression of pain."

- Charlie Park

You might like to explore more about Autistic pain here.

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



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Autistic social communication differences

Autistic people have a full range of feelings and emotions. How each person expresses emotions and the level of their ability to express emotions varies.

It's important to support a person who is expressing their emotions by validating their emotional response, paying attention to their body language, being patient, and helping them to utilise communication strategies.

As part of the social communication differences associated with Autism, it is not uncommon for Autistic people to have trouble recognising and interpreting emotions (this is called alexithymia), which can add to the misunderstanding about Autism and emotions.

It is important to remember that Autistic people have emotions, are caring and loving, and their feelings can be hurt, just like anyone else.

Autistic empathy

"Some people have told me that I'm cold because of my response to their hurt. I don't naturally do 'oh, that must really suck for you' or 'poor you'.

To my brain this response feels superficial and meaningless. I feel other people's hurt so deeply that I want to help them from experiencing this ever again.

My highly interconnected Autistic brain goes into hyperdrive; searching for knowledge and my own experiences that might shed light on solutions. I probably appear flat and disengaged because I'm highly focused on helping. Some people think this means that I don't care.

When I find a potential matching experience, I run it by the hurt person to check if I've understood their experience. Some people interpret this as grandstanding - 'I've had it worse than you'. But it's not about me. I'm 100% focused on them.

I use this information to identify the issues that lead to the hurt and generate solutions for preventing it's recurrence. When I deliver my findings, some people think I'm blaming them for causing their hurt.

They think I'm saying 'if only you did this, you wouldn't have been hurt'. They lash out at me, calling me 'cold', 'hard', 'blunt'. It's deeply deeply hurtful to me to sit intimately in someone else's hurt for them to pile more hurt onto me.

I've learnt that with most people, it's safest to block off the empathy part of my brain and force out the words 'there, there'. I'm a terrible actor so this probably looks fake, but it seems to cause less offense than my natural processing.

I wish for a future where neurotypical* people accept the different perspectives of the Autistic brain."

- Charlie Park



For more information about Autistic empathy, you might like to watch a <u>video</u> on the subject, or read a research summary about '<u>the double empathy problem</u>' (see p. 23 of this Welcome Pack).

* For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Reflection

Take a moment to consider the importance of differences in Autistic communication, socialising and empathising, and how these might look different for different people. What are some of your organic Autistic communication preferences or needs? How do you like to connect and socialise?

If you like, you can note your thoughts on page 27 of the Workbook.



In our own words, these are the things we wish others knew about relationships, overcoming barriers, and growing our potential...



Autistic desire for social connection



Autistic people often have very strong bonds with important people in their lives. They can and do have fulfilling relationships with family, friends, partners and children.

Studies have shown that most Autistics want to form relationships with others. For some Autistics, it can be difficult to understand non-autistic social cues and to navigate typical social interactions, just as it can be difficult for non-autistics to understand Autistic social cues and interactions. It is important to recognise that appearing uninterested is not necessarily the same as being uninterested.

There are a variety of strategies that can help support social connections (like structured interactions and planned events around shared interests).
Relationships are always a 'two-way street', and success is never the responsibility of only one party.

Autistic people may experience social anxiety because non-autistic ways of socialising may not be easy to understand. This might mean an Autistic person appears quiet and shy and might avoid social situations, while others might speak too much and 'infodump' to cover their anxiety.

Many Autistic people speak about how confusing some elements of unspoken communication can be: body language and tone of voice can be difficult to interpret, especially when combined with non-literal language use such as idioms and sarcasm (or not saying what you mean).

Making the effort to understand how your Autistic friend, loved one, or acquaintance prefers to communicate and socialise will allow them to express themselves authentically with you and show their desire for social connection.

You can read a summary of some research about '<u>Autistic social motivation</u>' on the Reframing Autism website. You might also be interested in some more information about being an <u>ally to the Autistic community</u>.

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Autistic friendships can look different

"As a kid, I liked playing with boys and family friends. At high school, I liked people across my classes, people from other year levels, and people from outside of school.

Later, I liked people who I sat next to at Uni, who I practiced yoga with each week, my work colleagues, my boyfriend's friends and people who I shared online experiences with. I counted all these people as my friends. I had plenty! I had this nagging feeling most of my life that I wasn't doing friends right. I'd look around at how other people did friends or see friendships on TV (e.g., groups of girls who all looked the same and did everything together) and mine were different.



But occasionally someone made it very clear that they didn't see me as a friend back or an older person would whisper about how I lacked friends of my own. This was confusing and hurtful.

When I was eventually diagnosed as Autistic, everything suddenly made sense! I realised that the neurotypical* world has a set of unspoken social rules about who you should be friends with and who counts as a friend.

Because I have a different type of brain, I don't have to follow these rules. How I friend is perfectly normal for me and for a whole community of other Autistic people."

- Charlie Park

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





Debunking the myth that Autistic people are not interested in social relationships



This is definitely not the case in my experience, and the experiences of my Autistic non-speaking* friends. We have a deep need for social connection, and for positive relationships with our community just like other people.

But due to our additional communication support needs and the lack of understanding of augmentative and alternative communication* by most folks, it is a challenge to join in with ease.

Furthermore, because of our sensitivity and processing issues, social events can be overwhelming, and we need to manage sensory overload by retreating to a quiet spot, far from the madding crowd. Our craving for social acceptance and approval will be taking second place with prioritising more urgent needs to self-regulate as the intensity of social situations with different conversations among people, other background noise and unpredictable movement add to our challenges. When we are seen as loners, or even people with social phobia, it is because we just can't mix or blend in comfortably.

- Tim and Sarah Chan

You can read a summary of some research about 'Autistic social motivation' on the Reframing Autism website.

* For a definition of terms, see the handy glossay on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Connecting with other Autistic people



"When I was first diagnosed as Autistic, I was advised that it was important for me to connect with groups of other Autistic people. However, I've learnt to value the friends that I already had and found ways to naturally attract new friends.

I've been fortunate that most of my existing friends have been accepting of me coming out as being Autistic. I realised that they had already accepted me for who I am.

Plus, I find it easiest to connect with people over shared interests, regardless of their neurotype*. I've found friends at yoga classes, girl-gaming groups and through my new disability advocacy work. Some of these people are Autistic, disabled, chronically ill, ADHDers, and others are non-disabled and neurotypical*. I'm happy to have all of them in my life."

- Charlie Park

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



No time for small talk

"Although some friendships seem to have dissipated since sharing my diagnosis, I have formed new friendships too, with other Autistics, both online and in real life. These are people with whom I found I had an almost immediate, intuitive connection.

We understand each other effortlessly.

And regularly, when I feel the need for connection, I'll reach out to these friends in the Autistic community, often in ways that may seem unorthodox to the neuromajority*, because we Autistics have no time for small talk – or perhaps I'll just send a meme and wait for their laughing emoji."

- Ginny Grant



*For a definition of this term, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/

Reflection

Take a moment to consider the importance of social connections, friendships, and romantic relationships for you. How important are 'important others' in your life? What characteristics do you value in others?

If you like, you can note your thoughts on page 28 of the Workbook.





Advocating for our needs

Autism is lifelong. If you're an Autistic child, you will grow into an Autistic adult.

In the past, Autistic adults have been overlooked in research, so instances and presentation of Autism in adults is an emerging area of research.

This also means that in the absence of research, our community has felt compelled to contribute to building our awareness and understanding of Autism. This has included advocating for our own needs and rights.

We know that the more we can learn about Autism through actively pursuing opportunities to diversify Autistic research, the more our community becomes equipped with the information we all need to thrive as Autists.

This in turn will bolster our advocacy work (and ideally render it redundant!).





Supports that benefit Autistic people often benefit everyone

"I was told off at a job once for 'not coping well with change'. Apparently, me wanting to talk a lot about the change with my colleagues/supervisor and wanting to plan for it in careful detail so as to ensure minimal disruption to clients and everyone's work equalled me not liking change.

This is actually an ableist* attitude - that everyone is capable of coping with change quickly, without question/consultation and they can continue performing well with uncertainty and things moved around.

Some of us have brains that do not work like this. **We shouldn't be discriminated against for our neurology**.

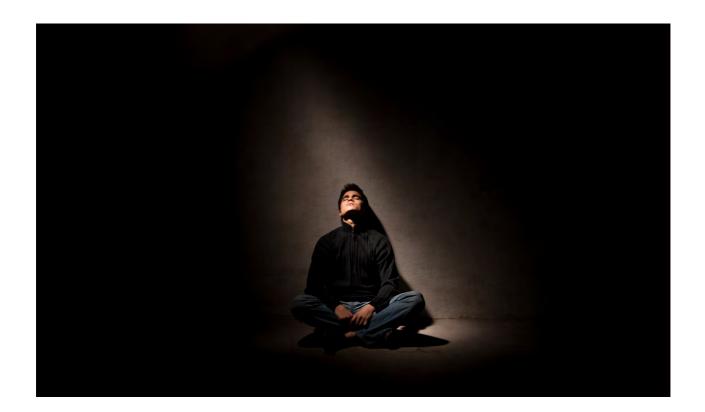
All we need is extra time, discussion and planning. This approach tends to achieve superior outcomes for everyone anyway."

- Charlie Park

For some more thoughts on 'Autism, ableism, and the key to self-acceptance', you might like to read this <u>blog</u>.

*For a definition of terms, see the handy glossay on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/





I need support to access my potential

"For me, I want others to know:

- It's hard and tiring living with constant anxiety, a busy mind and navigating a world where I'm going against the flow.
- I'm intelligent and capable but I find it hard to tap into my capacity and fulfill my potential because there's so many barriers (pragmatics, networking, sensory differences, executive functioning, anxiety).
- I need help to access my potential –
 ask me and help me work out what
 strategies would help me access my
 potential. Don't just guess or go with a
 prototype of what you assume helps.

- I need reassurance, clear expectations, tasks broken down into manageable steps, knowing plans in advance - don't like the unexpected.
- I do small talk because it makes you comfortable. But I find it uncomfortable and pointless.
- I may not seem 'Autistic' but that's because I've learnt over the years how to fit in (mask*) - how to minimise my differences in order to be accepted and not considered 'weird.'
- It can be lonely I long for close friends and regular social events and catch ups, but many things make that difficult."

- Jenny Mitchell

^{*} For a definition of terms, see the handy glossary on the Reframing Autism website here: https://reframingautism.org.au/service/glossary-terms/



Develop awareness of your access needs

"I'll never forget that for my first disability advisory committee, I requested they provided handouts or slides for meeting items. I was told 'some people prefer a formal meeting, we like ours casual'.

Being Autistic, I took this as a true but a somewhat random observation to be making. I waited for them to action my access request. And waited. Nothing happened. My Autistic brain (including auditory processing, comprehension and working memory difficulties) struggled to follow their purely spoken meetings. I was getting headaches after each meeting from concentrating so hard to keep up. After nearly a year of this, I had little choice but to resign.

Several months later, my brain finally finished processing their initial response to my request (yep, it's that slow sometimes). I realised that they thought that I was requesting slides because I liked formal meetings! What an odd interpretation, especially when I raised it in the context of a discussion about access needs.

This has happened to me other times too - many people (even in the disability industry) do not understand the access needs of Autistic people. To them, having a quiet workspace or having extra breaks are preferences, optional extras or perks even. But to Autistic people, these are essential access needs - we cannot work without them.

We need much greater awareness of our access needs."

- Charlie Park



Autistic strengths: We have much to offer



"I wish the world to know that we have much to offer, in cultural contribution, in all walks of life. We have extraordinary skills and insights. We do think laterally, and outside the box.

We are skilled in academic pursuits, in creative pursuits, and can and do contribute to the betterment of human life.

We have an edge that offers unique

insight that can propel society and nations forth. We have skillsets that can problem solve and innovate. Our empathy connects us. **We have strengths**.

We can and do make a real difference to the world in which we live, just let us show you what we can do and see for yourselves who we are..."

- Stormy Meiying Liu



Reflection

Take a moment to consider all that you have to offer the world! Reflect on the barriers you have overcome to experience success and thriving. Note your thoughts here.

If you like, you can note your thoughts on page 29 of the Workbook.



Thank you

Thank you for taking time to engage with us and our stories.

We hope our stories have given you an opportunity to immerse yourself in our community and begin to discover your unique Autistic self.

We also hope you were able to engage in the process of reflecting on some of your Autistic experiences along the way, by using the various prompts offered.

As a final reflection, take a moment on the next page to consider where your information about Autism comes from now, and how this continues to contribute to your Autistic identity.



Final reflection

If you completed the initial reflection task on page 17, you might like to now complete this final reflection. Take a moment to consider where your information about Autism comes from now that you have engaged with this Welcome Pack. How does your knowledge continue to contribute to your Autistic identity?

If you like, you can note your thoughts on page 30 of the Workbook.



Further Resources 176

Further resources



Further Resources 177

If you would like to continue learning about our community, take a look at the following page, which links you with further resources.



Further Resources 178



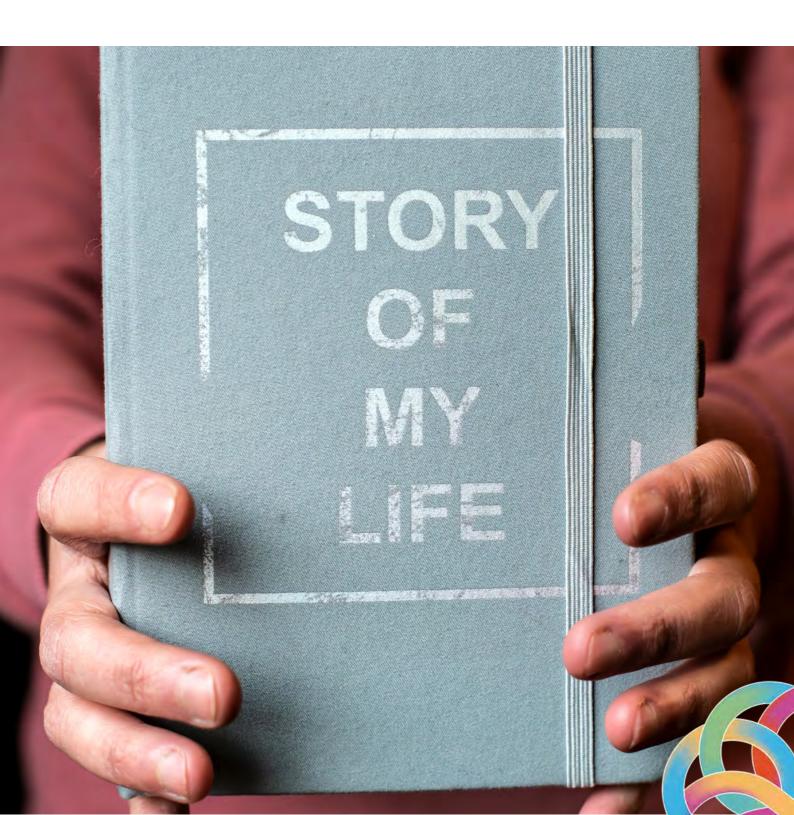
Resources and Authors/Websites:

- <u>I am newly diagnosed</u> Amaze
- When a late diagnosis of Autism is lifechanging
 Abby Sesterka and Dr Erin Bulluss
- Post diagnosis and disclosure
 Academic Autistic Spectrum
 Partnership in Research and Education (AASPIRE)
- Character strengths adult survey Authentic Happiness
- Post diagnosis support for Autistic adults
 National Autistic Society
- NeuroClastic The Autism Spectrum According to Autistic People NeuroClastic
- <u>Discovering your Autistic identity as an adult</u>
 Reframing Autism
- Thinking Person's Guide to Autism: evidence-based, neurodiversitysteeped information from autistic people Thinking Person's Guide to Autism (TPGA)

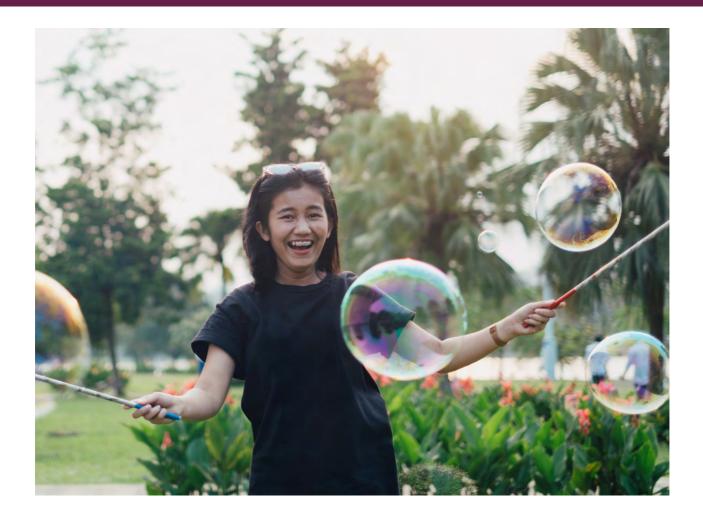


Biographies 179

Contributor biographies



Biographies 180



Contributor biographies

At Reframing Autism, we work across research and lived experience to educate the Autistic and broader communities about Autism, and to challenge incorrect stereotypes that cast Autistic people as 'broken', 'impaired' or 'disordered'.

It is these extraordinary individuals who bring their varied lived-experience and multiple intersectionalities who have contributed to this Welcome Pack, to make it what it is.

Across the following pages, you can read our stories to learn about your fellow Autists.

- Alex Pilgrim
- Charlie Park
- Ginny Grant
- Hem (aka Sid) Chandran
- Jenny Mitchell
- · Natasha Siryj
- Sarah Climpson
- Shazzy Tharby
- Stormy Meiying Liu
- Tim Chan
- Alexandra Johnston



Alex Pilgrim

My name is Alex or Pie. I use they/them or He/him. I refer to myself as a masculine person rather than subscribing to gendered language. I prefer not to use 'preferred' in relation to pronouns. Being 'gendered' correctly is not optional it's a requirement to be respected as a person.

I live on the lands of Perth aka Whadjukor Noongar people.

I am Gender diverse; transgender male, masculine person and non-binary, Queer, Neurodiverse in a few other diagnoses or rather 'ways of being' such as a person with ADHD and Dysgraphia.

I prefer not to introduce myself disability first, person first is my normal. I am an autistic person; I received my diagnosis in my mid to late twenties. I sought out diagnoses for two other neurodiverse conditions within the two-year time. I also belong to the gender diverse and queer communities.

Like many other Autists I live with chronic health conditions including emotional distress conditions. I mention 'emotional distress' as alternative language to describe my mental wellbeing aka mental health. I consider referring to emotional or mental distress experiences as problematic as using the word 'issue' patronising.

As a preamble my achievements are humble and may come across as 'settling for less'. I love myself enough to celebrate the things I can within my limited by external factors outside my control.

- Successfully gaining access to the NDIS and Disability Pension
- Navigating tertiary education system that is not built to accommodate neurodiverse learning requirements.
- Attending university and working through relearning how to be a student with multiple neurodiverse conditions. It was a rough time to learn on the go mid degree without practical guidance from peers.
- My greatest achievements are my resilient fighting spirit, resourcefulness, research, my perspective.

I am passionate about various arts and crafts such as designing and creating clothing. I like being outdoors. I like to try new things including things outside my comfort zone to a reasonable extent.



Charlie Park

Charlie (she/they) is an influential Disability Consultant and Writer who understands disability from the inside and out. Starting her career in management consulting and corporate HR, Charlie collected skills in training and meeting facilitation.

During her second career, she completed a Doctorate in clinical child psychology, published research on Autism, and worked for 15 years with children with disabilities and mental illness.

When chronic illness interrupted her career, Charlie embraced new-found identities as a disabled Autistic non-binary human and she became an advocate for her communities.

Charlie is making healthcare and disability supports more inclusive and accessible, and promoting disability acceptance and neurodiversity.

Her advocacy highlights include:

 Co-creating Australia's first Disability Pride Mural.

- Successfully advocating for multiple lived experience roles to be paid positions.
- Being a founding member of Women with Disabilities Victoria's Experts by Experience Group.
- Being a community blogger for Invacare.
- Appearing in educational videos produced by the Growing Space.
- Representing COVID-high riskers in a Sydney Morning Herald article.
- Providing advice to the NDIA about their Participant Safeguarding Policy and speaking about participant rights on a Hire-Up panel.
- Creating the blogs Chronically Crappy and Not My Bread and Butter.

Follow them @MeanderingPark.



Ginny Grant

My name is Virginia, but most people call me Ginny. I use she/her pronouns. I live on the lands of the Gadigal and Wangal people of the Eora nation, also known as Inner West Sydney. I'm a neurodivergent parent of neurodivergent children. My life changed forever when I brought my two children into the world and soon discovered they had wonderful brains that seemed to differ from the neuromajority. Not long after their Autistic identification, I realised that I shared many atypical traits and experiences with my children. I was formally identified as Autistic at the age of 39. I use identity-first language, because Autism – and more broadly neurodivergence – is an important part of who I am. I am Autistic, and my brain diverges in multiple other ways too: anxiety, depression, OCD, PTSD and, to top it all off, a relentless restrictive eating disorder. Many years ago, I studied a Bachelor of Arts with Honours in Philosophy, because I went down a special interest rabbit hole at the age of 17. I wrote my thesis on Edmund Husserl's Phenomenology. Don't ask me about it now, though - I wouldn't have the foggiest idea! In 2020 I came on board as Reframing Autism's (RA) Communications Manager. In that role, I ran the social media and produced many resources for the organisation. Heft RA in 2022 to pursue my other big passion: book editing, which I've done for the past 20-plus years, because it turns out philosophers specialising in phenomenology are not especially employable. I'm still very proud of what I achieved at RA.

I have spoken and written about my lived experiences of Autism and mental illness quite extensively. Here are some of my advocacy achievements:

- Wrote numerous articles for RA's website
- Hosted the first two seasons of RA's podcast, Amplified: Autistics in Conversation with Reframing Autism
- Co-hosted RA's 2021 Autistic Mental Health and Wellbeing Conference
- Co-hosted two RA parent retreats
- Presented on various topics as part of RA's Autism Essentials course
- Editor of Just Right for You by Melanie Heyworth (RA)
- Spoke on the London Autism Group Charity's podcast, The Autism Podcast (Episode 26)
- Spoke on The Spot Therapy Hub Podcast (Episode 4)
- Spoke on Aucademy's Eating
 Disorders in the Community webinar
- Spoke at Yellow Ladybugs' 2021
 Mental Health and Safety Conference
 (now Episode 5: Complex Mental
 Health of The Yellow Ladybugs
 Podcast)
- Editor of Supporting Autistic Girls and Gender Diverse Youth by Yellow Ladybugs
- Panellist in Yellow Ladybugs' PND and Neurodivergent Parenting webinar
- Editor of So, You're Autistic by Yellow Ladybugs

However, by far, my greatest achievement is raising two children who inspire me every day with their kindness, courage and creative minds.

You can find me online at LinkedIn (Ginny Grant) and Instagram (@virginia_lily_grant).

Hem (aka Sid) Chandran

My name is Hem Sidharth Chandran. I like to be called Sid. My pronouns are he/him. My identities are as a person of migrant background who has dark skin colour. I identify as a non-speaking autistic. I also identify as a published author.

I am on Wallumedgal Country. I am an AAC user. I use the iPad as a speech generating device. I use the Alpha Core from the Grid app.

My main struggle is inability to find suitable AAC options. Due to my apraxia, I experience issues in accessing my Grid AAC independently. I need support to keep the device ready for my use. This is an issue that technology needs to address as it poses a huge limitation for AAC users like me.

There are a few things that I want people to know about me. I have a good understanding of spoken language.

People frequently miss that. This creates a vulnerability for non-speakers like me. We are often exposed to negative comments and to being talked over. I would like people to be mindful of their words.

I work as an AAC mentor with AGOSCI. I have done a number of seminars mainly about AAC and my published book. It has been a learning experience. I have done presentations on my experience with AAC. I believe these presentations will be useful to others who use AAC. I have contributed a module on Words Matter-Presuming Competence to the Autism and Neurodiversity Masterclass. This is an online learning program.

I have a website <u>Unspokenstory.com.au</u> on which I blog about everyday events that I want to share as well as my views and observations on topics that matter to me. I have recently published a book on living with autism titled **An Unspoken Story**.

I hope it will help people who are nonspeaking and diagnosed with autism. I wrote it so people don't feel like they are alone in their Autism journey. So there is an intent to advocate and self advocate.

I am a writer. I presented my recently published book at conferences and other forums. I am an advocate for AAC users and spellers. I am interested in nothing more than advancing research projects that look into the technology of AAC.

I have been thinking about the backlash against supported typing. The issues raised against it need reframing. Each objection is an important area of research. I am so serious about it that I will blog about this topic. My proudest achievement to date is my book.

Jenny Mitchell

Jenny is an experienced educator (Bachelor of Education). She enjoys using her skills to give presentations, workshops and to write about lived experience.

Jenny is a late diagnosed Autistic woman, who spent many years undiagnosed, with her challenges attributed to her intersectionalities - a chronic eating disorder and being a transracial adoptee.

She was later diagnosed with inattentive ADHD when the cognitive load of running

a family challenged her already overfunctioning limits.

Jenny is passionate about sharing her lived experience to raise awareness and understanding. Jenny desires to help others struggling with similar experiences by validating their experiences and offering insights. Jenny has presented in Sydney and internationally.

In her spare time, Jenny enjoys keeping fit, massages, reading, and sipping prana chai.



Natasha Siryj

Natasha (she/her) is a late diagnosed Autistic and ADHDer. She is a qualified teacher, has undertaken educational research and has worked in a variety of settings including community services, education and local government.

Natasha has presented at conferences and symposiums, sharing her own Lived Experience of being an Autistic individual, and has been a speaker on Lived Experience storytelling, consultancy and co-design. Natasha seeks opportunities to use her intersectional lens and Lived and Living experience to build awareness.

She is passionate about inclusive practice, the power of individual voice and the use of Lived and Living experience to drive change. She encourages others to form a better understanding of Autism, other Neurodiversities and Mental ill-Health, and aims to build awareness about including and the value of Lived Experience.

Natasha has her own training and consultancy business, **Practice Inclusion**, and is also the chair of the IAC.



Sarah Climpson

Sarah (she/her) is a late diagnosed Autistic woman, who lives with her husband and two young neurodivergent children on the beautiful Wathaurong land in Victoria, Australia. Sarah is a second generation Australian of Anglo-Saxon and Mediterranean heritage, and she values cultural diversity and the richness that this brings to experiencing life. Along with being Autistic, Sarah also has ADHD, chronic illness, and both physical and psychosocial disability.

Sarah studied Health Science at university, and following this became a practicing Advanced Life Support Paramedic in 2012. Sarah then lectured in the paramedicine discipline in a university setting and gained postgraduate qualifications in tertiary education. Sarah has a passion for education, for learning and for facilitating the sharing of knowledge and experiences; ultimately, she was able to channel this passion into her current vocational role as a performance and coaching lead within a large social insurance agency.

Sarah is involved in lived experience work with several organisations, including the National Disability Insurance Agency and Safer Care Victoria. Sarah believes strongly in disability advocacy and in codesigning with lived experience consumers. She values the opportunity to be involved in projects which seek to understand and improve the experiences of people living with disability, especially in the workplace and in accessing healthcare.

Outside of her vocational adventures, Sarah deeply enjoys being outside on her property and surrounds where she can experience the simplicity of nature.

Gardening is a favourite pastime, and Sarah also enjoys cultivating her indoor plant collection. She loves keeping busy and always has many projects on the go. Her children are a very important part of her life, and Sarah considers herself blessed with the family she has and the opportunity for introspection, growth, and evolution that parenthood has presented her.

Sarah prides herself on her desire to critique and challenge social constructs and stereotypes, and wears her labels proudly on her sleeve. She is no stranger to speaking up and gently, yet passionately, educating and uplifting those around her to practice acceptance and inclusion. She hopes that one day grace, humility and empathy will triumph and we will find ourselves in a newly created culture which embraces differences and celebrates uniqueness.

At any given time, you will likely find Sarah with a coffee in hand, musing over and editing her 'to-do' list, and wondering what it was exactly she was supposed to be doing before she became distracted by the song stuck on repeat in her head.



Shazzy Tharby

Shazzy lives and works on Whadjuk
Noongar Land. Originally hailing from the
UK, Shazzy embarked on a global
adventure before finding her heart in
Australia. Shazzy studied at Cambridge
University and now holds a rainbow of
qualifications besides her Nursing
including a Post Graduate Degree in
Counselling and Psychotherapy and is
now undertaking her Master's in
Psychology.

Shazzy has been on a mission to champion neurodiversity, disability and mental health for 30 years and isn't stopping anytime soon. By day, Shazzy is a Clinical Nurse Consultant and Counselling Psychotherapist, sprinkling appropriate amounts of support and positivity to her clients whilst training people in mental health and neurodiversity, clinically supervising, mentoring and advising businesses at her private practice,

Positively Living.

Rolling through life as a wheelchair user, juggling a kaleidoscope of co-conditions, Shazzy embraces her identity as a biracial, multilingual, autistic, ADHDer, PDAer powerhouse. Together with her rockstar spouse, Alex, she is navigating the wild ride of raising two neurodivergent gems.

When Shazzy is not busy advocating for marginalised voices through an intersectional lens or serving on committees and boards you'll find her cosied up in her favourite fluffy blanket writing informative articles on LinkedIn whilst sipping tea and plotting her next grand adventure. Shazzy doesn't like to give advice, she likes to give people information because everyone's life is different, and everyone's journey is different. She believes in spreading love, laughter and inclusivity wherever she goes.



Stormy Meiying Liu

My name is Stormy. My pronouns are she/her. I live on the lands of the Wadawurrung and Dja Dja Wurrung People.

I am a blind woman identifying as Autistic with ADHD, am a mature age Autist, exploring how my life is blending with my Autism and ND whilst integrating these aspects of myself into my life since childhood and adolescence.

Change is no stranger to me, my blindness adds a unique perspective and also has impacted on my Autism to a large extent. I do not see these parts of myself as mutually exclusive.

I have a long history of activism, especially in disability rights. As an advocate and activist, I feel my lived experiences inform my work with the IAC, and community.

Through my activism, I have media experience, public speaking skills in community politics. I gained my BA with Honors, majoring in English, I am proud of my academic achievements: skills in communication, writing and editing, negotiation skills. My working life in sales and office equipment, I enjoyed and acquired PR skills and office acumen, I also worked in the insurance industry.

Working on my first novel project, and online journalling. hope to be starting my own business: negotiations, contributing to generating ideas, taking a lateral approach.

My passions - interests, my love of birds, a strong connection to the living planet. I am

passionate about Godzilla, (a Titan), the role Godzilla plays with his Titans in defending the planet, life, including us. I also love birds and butterflies and living world generally. Audio books, and am passionate about a series, 'Hell Divers' a post dystopian epic, led by the protagonist, Exavior Rodregous, or Ex, and genetically modified Husky, 'Miles' (the author, Nicholas Sansbery Smith).

I am a composite of things, beyond what I have said about myself, I love my creativity, my interest in Earth Spirituality and Witchcraft, a member of the LGBTI community.

I feel I have done the hard work most of my life and feel rejuvenated. I am passionate, optimistic, and determined to make my mark on this world, and to shine.

I wish to dedicate myself to making a difference, no matter how big or small.

I want the world to know, I will throw myself into the battle for a better world, a better life and major institutional reform.

My call to action, changing the face of Australia in my spheres of influence creating a more equal society, better governance and seeing the end of managerialism and ageism.

My greatest achievement, gaining my undergraduate degree with honors, live a full life, taking courage from my life's ongoing journey. My motto: 'I am beautifully flawed', there is no retribution, no blame, only stepping stones.

Tim Chan

Tim Chan (he/him) is a 28-year old Chinese Australian. He was diagnosed with Autism at 3 years old, and has been non-speaking after 14 months of age.

At 9 years old, after picking up AAC in partner assisted typing, Tim became opened to the possibility of connecting with people and with the life he wanted to live. He has worked on building his capacity and strengths, especially in communication. His journey has been supported and scaffolded by his social network.

Lived experience of exclusion at high school, such as the prohibition of his preferred mode of communication, has motivated Tim to persevere in formal education to build his capacity and strengths, with the support of his social network. He completed his BA, and BA Honours, and is currently engaged in PhD studies on the Neurodiversity movement in relation to individuals with additional communication needs.

Some of the highlights of this journey include giving a TED Talk when he was 18, presumably the first by a non-speaking Autistic person, and writing his autobiography, **Back from the Brink**.

With enormous respect for organisations that advocate for Autism, Tim is excited to be part of the self advocacy movement, to drive Autism to new levels of relevance and inclusion.



Alexandra Johnston

Dr Alexandra Johnston (PhD) is an Autistic postdoctoral autism researcher with the Autism Centre of Excellence, Griffith University and Reframing Autism.

Alexandra is also an accomplished educator with 25 years' experience in the areas of early childhood and applied positive psychology.

Alexandra is a member of the Australasian Society for Autism Research (ASfAR) and a board member with Inclusive Rainbow Voices, where her specific expertise in trauma-informed practice supports codesign research initiatives with community representatives from under-represented and multiply marginalised groups.

As an interdisciplinary lived-experience researcher, Alexandra is a research fellow

as part of a diverse team of academics from the University of Glasgow, the University of Melbourne, and the Australian Catholic University. She has presented her research at international conferences, where her focus spans contemporary theory and practice within Autistic wellbeing and applied positive psychology.

Alexandra's special interests include understanding experiences of Autistic wellbeing and thriving. As the Co-Design Lead for the Welcome Pack, she very much looking forward to hearing from you if you would like to share your own experiences of Autistic thriving – especially after reading our Welcome Pack!

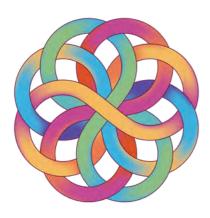


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You are welcome!

www.reframingautism.org.au

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