

Reframing Autism

2021 Annual Report



reframing
AUTISM

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Letter from the CEO

Dear Friends,

Last year, when it came time to write the 2020 Annual Report, I remember thinking optimistically of writing this year's report, with a confidence that 2021 would have seen fewer disruptions to Reframing Autism's activities, and a general upturn in the state of the world post COVID-19. And yet, as I sit down to reflect on the past year, it has yet again been punctuated by lockdowns, restrictions, isolation, and, of course, interruptions to plans.

Yet, despite COVID-19, this past year has been monumental for Reframing Autism. We have grown significantly, both in staff and program participants, we have crystalised our strategic plan and purpose, and we have delivered high-quality, inclusive, and accessible programs globally thanks to newfound online delivery methods.

Proudly, our operations team continues to be 100% Autistic, and we continue to prioritise contracting and hiring Autistic experts to support our program delivery whenever possible. We showcase Autistic-produced resources across all of our platforms, and we are honoured to have worked with 45 Autistic contributors in 2021, all of whom were paid for their expertise and time.

Equally as proudly, each Director of our Board identifies as neurodivergent, with seven of eight Directors identifying as Autistic. Significantly, all operational management positions, and all senior management Board positions, are filled by Autistic individuals, who bring their lived experiential knowledge to enrichen our organisation. We are, then, truly Autistic-led.

We have had the opportunity to work alongside, and to explore new alliances and collaborations, not only with other Autistic-led organisations, like The Autistic Realm Australia (TARA), but with other not-for-profits and charities whose work aligns with Reframing Autism, but who are not firmly in the "Autism space", like Minus18.

Our activities in 2021 have demonstrated our deep commitment to improving the quality of life and wellbeing of the Autistic community, and the allies who support us. The Autistic community still faces significant challenges: stigmatisation, discrimination, marginalisation, poor health and wellbeing outcomes, under- and unemployment, financial distress, and educational and social exclusion.

Very few organisations are attempting to address so many of these needs systematically and simultaneously as Reframing Autism is, but we are certainly not challenging the status quo alone. We have a large global community of Autistic individuals and organisations, and steadfast allies, who stand beside us to defy the soft bigotry of low neuronormative expectations that would see the Autistic community disregarded and oppressed, by showcasing our enormous strength, worth, and value both individually and collectively.

In this 2021 Annual Report, we will give you some specific examples of how we are achieving positive change for the Autistic community, and highlight some of our most significant achievements for the year.

It has been my privilege to lead Reframing Autism as its CEO again in 2021, and I am humbled, awed and unutterably proud to work alongside my dedicated colleagues, my Autistic neurokindred, and our committed allies, to bring about much-needed change.

With thanks



Melanie Heyworth
CEO & Founder



The background of the slide is a vibrant watercolor illustration. It features a variety of fish in shades of pink, purple, blue, and yellow, swimming in a light blue and white aquatic environment. The water is depicted with soft, blended washes of color, and there are numerous small, colorful dots and splatters scattered throughout, giving it a dynamic and artistic feel. The overall composition is bright and cheerful.

Education

“ Education is the most powerful weapon which you can use to change the world. ”

– Nelson Mandela

In summary, we

- Co-hosted (with Aucademy, UK) an international online, multi-day conference on Autistic Mental Health and Wellbeing
- Co-hosted (with TARA) a one-day, single-stream online symposium on Intersectional Identities: Autism, gender, sexuality
- Hosted a one-day, single-stream online symposium on Autistic Flourishing: Acceptance, authenticity, autonomy
- Offered a range of parent educational opportunities, including introductory workshops, intense parenting retreats, and “deep-dive” masterclasses
- Facilitated introductory and continuing professional development workshops for allied health professionals and educators, including bespoke commissioned training for interested allied health organisations

Just prior to the Intersectional Identities symposium, an Autistic, multiply disabled teen contacted us to apply for a scholarship for themselves and their parents to attend the symposium. The teen explained that they had struggled with their LGBTQIA+ and Autistic identities, and consequently had few friends, although they were desperate to connect with other Autistic teens who identified as LGBTQIA+. The teen was keen to develop their advocacy skills, particularly to advocate for educational equity for their multiply neurodivergent peers.

Due to their complex family circumstances, the teen and their family were not in a financial position to attend the symposium, and we were thrilled to have specific sponsorship from Minus18 to facilitate attendance at the symposium for under 25s.


After the symposium, the teen's feedback was that they had loved learning about themselves through the presentations, and about the different ways that could self-advocate and advocate for their peers. They also credited the symposium with increasing their non-disabled mother's empathy for, and access to, their lived experiences as Autistic and LGBTQIA+. They felt the sex education presentation by Dr Emma Goodall was particularly relevant and important to their life as teenager, and spoke of the value of being heard, represented, and belonging to a community.

This teen no longer felt alone.

One of the teen's parent's feedback was similarly affirming, since the symposium provided a locus of education and connection that built the young person's confidence personally and as an advocate, simply by recognising that the Autistic-LGBTQIA+ community is valued and important.



Resources



Words do two major things: They provide food for the mind and create light for understanding and awareness.

– Jim Rohn

In summary, we produced

- A podcast series, entitled *Amplified: Autistics in conversation with Reframing Autism*
- Guest and team-authored blogs and tip-sheets, including a multipart Introduction to Autism series
- A position statement on the needs of the Autistic- LGBTQIA+ community
- Layperson, accessible summaries of key research of most importance to the community
- Foreign language translations of our blogs on “The importance of identification” and “The gift of unconditional love”, and the tip-sheet on “Talking to children about Autism” (in Arabic, Mandarin, Vietnamese, Punjabi, Hindi, Tagalog, Traditional Chinese, Italian, Greek and Spanish)
- Easy English translations of position statements and research summaries
- Webinars for free access on our YouTube channel
- A second edition of our picture book, *Just Right for You*, now available to purchase online and in bookstores

Producing resources has always been a cornerstone of Reframing Autism's activities, and we take pride in paying Autistic experts to help the team to produce relevant and meaningful resources to appeal to our diversity of stakeholders, including Autistic people themselves, family and friends of Autistic loved ones, and the allies and professionals who support the Autistic community.

This year, much of our focus has been on making our resources accessible to the broadest possible audience, and to understanding the needs of our stakeholder communities to provide more targeted, impactful resources.

For example, one way in which we have demonstrated our commitment to our multicultural audience is to translate some key introductory resources, like blogs and tip-sheets, into a variety of languages, so that culturally and linguistically diverse communities are able to access some of our resources in their native language.

We also began to translate peer-reviewed academic research into comprehensible, layperson summaries, so that the broader Autistic and Autism communities might have access to the research of most relevance to them and to their lived experience. We quickly realised, however, that even in a layperson summary, these "translations" were inaccessible to those in our community with an Intellectual Disability, with learning differences, or with limited English literacy. We thus commissioned Scope to render the summaries into Easy English, so that the information was accessible to all, not only to a privileged some.

At the same time, we commissioned Scope to translate our position statements (on Early Intensive Behavioural Interventions and on the Autistic-LGBTQIA+ community) into Easy English, so that no individual was denied access to information of relevance to them.

We will continue to publish key resources in foreign language and Easy English translations going forward, to ensure that knowledge is accessible to everyone engaging with Reframing Autism.





Research



No research without
action, no action
without research.



– Kurt Lewin

In summary, we

- Launched the Autistic Research Network (“ARN”)
- Gave keynote presentations at the Australasian Society for Autism Research and the Aspect Research Centre for Autism Practice conferences
- Gave papers at other local conferences
- Were published in key academic, peer-reviewed journals (including *Autism*, *Autism & Developmental Language Impairments*, and *Autism in Adulthood*)
- Represented the community on the Australasian Autism Research Council, and as advisors and co-researchers on various research projects of importance to the Autistic community

Reframing Autism argues that autism research needs to be both participatory and emancipatory in order to impact positively the lives of Autistic individuals across the lifespan. In 2021, we launched the Autistic Research Network, the vision of which is to create an environment where authentic co-production is a standard and expected practice in autism research, where Autistic contributors are included regardless of support and communication needs, and where autism research is guided by the priorities and needs of the Autistic community and their allies.


Research networks have been utilised in other disability sectors to include the voices of those who most need to be heard in research: the “researched”. Research networks ensure that the researched community are established as equitable research partners to ensure first-hand information and perspectives inform research priorities and outcomes. Such networks facilitate research that circumvents observer bias and values direct experiential knowledge, effectively determining relevant research questions, research design, and results interpretation, with the overarching goal of striving for systematic participation and meaningful change.

The ARN:

- emphasises that direct, lived-experiential knowledge is as valuable as academic research,
- empowers Autistic individuals, including qualified researchers and the broader community, to engage in all stages of autism research
- believes that the validity and relevance of autism research is dependent upon the genuine inclusion of Autistic voices – however they communicate – across all stages of the research process,
- asserts that the contribution of a diversity of Autistic experiences to coproduction is essential for meaningful, translatable, robust, reliable and significant research that actively contributes to the wellbeing of the Autistic community, and
- values diversity, and prioritising the voices of those who are especially vulnerable or multiply marginalised through their intersectional identities.

The ARN also hopes to challenge the status quo in Australian Autism research that has effectively created an “echo chamber” of privilege by relying on the same Autistic co-researchers, without empowering those in the community who are routinely silenced, stigmatised, and marginalised, such as those with high support needs, complex communication needs, Intellectual Disability, or with multiple intersecting identities.





Leadership

“ Leaders don’t create followers; they create more leaders. ”

– Tom Peters

In summary, we

- Prepared to launch an 8-module Certificate in Autistic Wellbeing for Autistics, for 20 Australian Autistic adults

Reframing Autism's commitment to leadership and advocacy has been focussed on developing the Certificate in Autistic Wellbeing. At the time of this report's publication, the Certificate is currently in its first iteration. The Certificate builds self-knowledge and launches advocacy careers by providing the foundational skills and knowledge to understand Autistic identity, and to apply that knowledge to improving the lives of Autistic individuals of all ages and their families.

In the 8-module intensive course, participants build the theoretical and scientific knowledge, as well as the practical application, to support their Autistic neurokindred to fulfil the conditions necessary for wellbeing in ways that are Autistically organic, respectful, and culturally sensitive. The Certificate thus fosters advocacy skills and empowers participants to use those skills to help the Autistic community to experience acceptance, authenticity, autonomy, and inclusion.

Through this online course – developed, designed, convened, presented and facilitated by an all-Autistic team – participants learn how to help Autistic individuals across support and communication needs in respectful and uplifting ways that actively build their – and the participants' own – wellbeing, using best practices endorsed by the Autistic community as well as innovative Autism research. Learning in the course is grounded in neuroscience and positive psychology, within the overarching frame of the neurodiversity paradigm.

Unlike other courses offered on Autism, Reframing Autism's Certificate is not only information-rich, but actively centres Autistic experience as meaningful, and approaches Autism from a perspective of building broad and genuine wellbeing for the whole Autistic community. During the Certificate, then, participants have access both to academic research, as well as to other Autistic lived expertise, which is considered as equally – if not more – valuable and valued as peer-reviewed academic literature.

In 2022, we hope to offer separate iterations of the Certificate in Autistic Wellbeing to parents and caregivers, to non-autistic professionals, and to Autistic professionals, as well as to Autistic individuals again.



2021 Impact report

Yearly highlights and impact

Worked with over

70 

Autistic contributors
since inception

Provided educational opportunities to nearly

800

Autistic individuals, and their
parents and professional all



Contracted and paid Autistic
contributors on

all

projects



Collaborated on

4

research projects



Supported a fully Autistic team of

8



employees through extended lockdowns

Maintained an

100%



neurodivergent Board of Directors

Events sponsored by

7

organisations



Over

35,000

followers across social media platforms



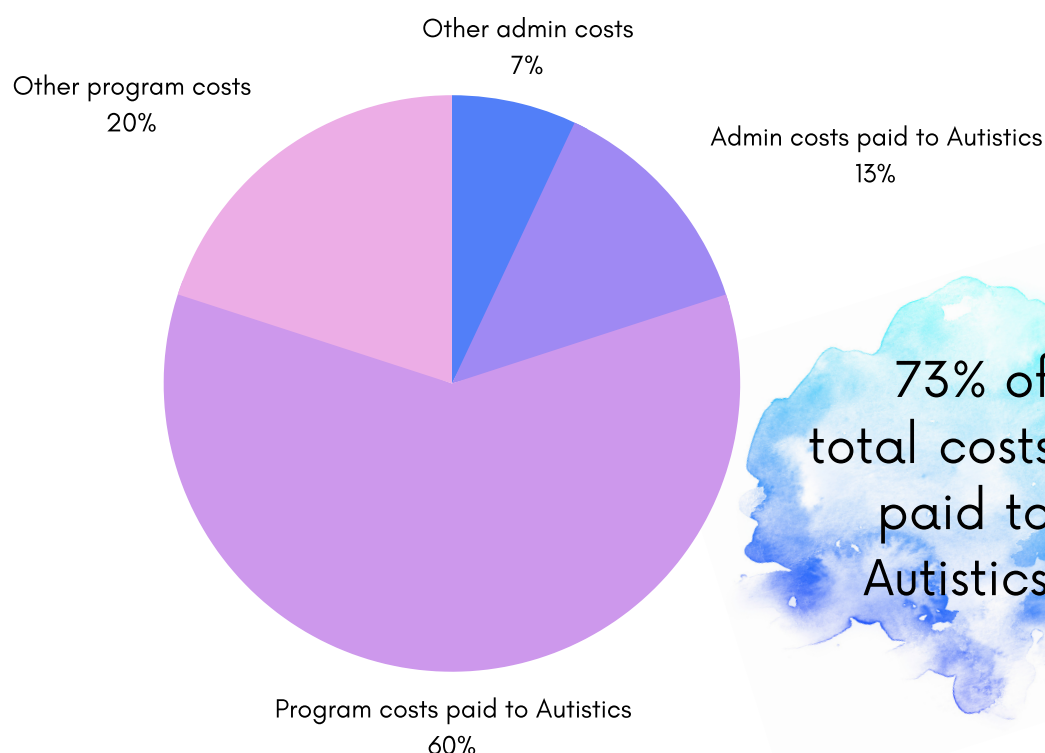
Reframing Autism's ultimate goal is to be redundant: to have changed the narrative surrounding Autism so effectively that we are no longer needed for education, support or advocacy. We are proud of our reach and impact in 2021, but there is still much work to be done.



Financial Highlights

Significant financial disadvantage is one of the most insidious challenges facing the Autistic community in Australia. According to current estimates, over 30% of Autistic Australian adults are unemployed (a figure six times greater than the average population), with 54% having never been employed, and 45% reporting underemployment compared to skills and training. Around 75% of Australian Autists report the Disability Support Pension as their main income, with only a meagre 6% reporting paid employment as their main source of income. One of Reframing Autism's abiding aims is thus to improve Autistic financial wellbeing wherever and whenever we can. Whilst we can only contribute to the financial security of the few through regular employment (with our Autistic staff), we also prioritise paying Autistic contractors, collaborators and consultants to ensure that we invest directly in our community.

With that purpose in mind, we are thrilled to announce that 80% of our overall costs in the financial year were spent directly on programs benefitting the Autistic community, with the vast majority of that outlay being paid to Autistic contributors and staff. We will continue our commitment to valuing the expertise and experiences of the Autistic community through paid opportunities to contribute to Reframing Autism in the next financial year.



During the year, the majority (82%) of Reframing Autism's income came from our Information, Linkages and Capacity Building (Individual Capacity Building) grant. This grant is multi-year, so this revenue was recognised in line with meeting the conditions of the grant (which approximates expenses).

Income from education and events revenues account for 17% of all revenues. These activities include both those initiated and run by Reframing Autism, as well as bespoke educational projects undertaken on the request of external organisations and individuals.

Donations and interest income account for about 1%.



Financial Statements

Statement of Profit or Loss for the year ended 30 June 2021

	2021	2020
	\$	\$
Revenue	520,055	69,458
Other income	1,725	98
Amortisation & depreciation expense	(1,919)	(117)
Bank fees & charges	(245)	(2)
Employment expense	(297,423)	(44,088)
Insurance expense	(5,962)	(1,311)
Technology expense	(17,401)	(6,880)
Other expenses	(143,612)	(15,477)
Net surplus for the year	55,488	1,681





Financial Statements

Statement of Financial Position as at 30 June 2021

	2021 \$	2020 \$
ASSETS		
Current assets		
Cash & cash equivalents	61,242	281,126
Trade & other receivables	260	200
Other current assets	326,678	10,183
<i>Total current assets</i>	388,180	291,509
Non-current assets		
Property, plant & equipment	5,055	4,155
<i>Total non-current assets</i>	5,055	4,155
TOTAL ASSETS	393,235	295,664
LIABILITIES		
Current liabilities		
Trade & other payables	15,985	8,963
Provisions	16,341	2,894
Other liabilities	303,740	282,126
<i>Total current liabilities</i>	336,066	293,983
TOTAL LIABILITIES	336,066	293,983
NET ASSETS	57,169	1,681
EQUITY		
Retained surpluses	57,169	1,681
<i>Total equity</i>	57,169	1,681

92%

of Reframing Autism's "people costs" spent with Autistic individuals where people related expenses are defined as wages and super for Autistic employees, contractors and other contributors/collaborators

10X

increased participation in Reframing Autism educational programs in 2021

Feedback

This workshop has rekindled my search for how to be a better parent to my autistic son – for a long time, I felt like I wasn't learning anything new or helpful but co-regulation ... wow. It's a real game-changer for me.

Really enjoyed and appreciated this informative presentation. So authentic and generous in sharing your experience and perspective.

This made so much sense to me – the neurology was especially helpful. And thank you for giving me the words to explain to the professionals we deal with that my kids aren't broken, they just need the right accommodations.

I am at a loss for words to express how validating your presentation is for me.

The information/content was like turning on a light bulb in my understanding of all the behaviours of my students ... Very valuable.

The gentle, reassuring tone and imagery complement each other beautifully. It is an insightful, accurate depiction of what it can be like to be autistic.

I am so grateful to have been a part of this retreat. It really helps to hear from Autistic adults' perspective ... It is great that Reframing Autism exists for families to learn more perspectives about the Autistic experience.

It really was very spectacular. I'm so impressed. Not only was every single presentation amazing, but the organisation and ease of use was out of this world.

Your personal narrative and educational content were brilliant – so relatable and powerful. It's so clear that having connections with the Autistic community and listening to Autistic voices is important for our clients and for us as professionals.



Acknowledgements

2021 Team

Sharon Fraser
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Dr Melanie Heyworth
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Emma Marsh
Kimberley Morcom
Rebecca Poulsen
Sophie Ralston

2021 Sponsorship Partners

Mable
AutismConnect (AMAZE)
ASAN Au/NZ
ANZ
Autism Camp Australia
The I Can Network
Minus18

Board of Directors

Kathy Isaacs, Chair
Gerard Atkinson, Treasurer
Dr Erin Bulluss
Tim Chan
Sharon Fraser
Dr Emma Goodall
Dr Melanie Heyworth, Secretary
Dr Justine Noble

With special thanks to ...

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One Stop Shop, Aberdeen
The Autistic Realm Australia (TARA)

Reframing Autism would especially like to thank the Autistic experts who have collaborated with us, for the wisdom and insights they have shared, and for their dedicated advocacy for the Autistic community.



“As for the future , your task is not to
foresee it, but to enable it.”
- Antoine de Saint Exupery

Questions, comments, or feedback on Reframing Autism’s Annual Report can be forwarded to:

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The Reframing Autism team would like to acknowledge the Traditional Owners of the lands on which we have the privilege to learn, work, and grow. Whilst we gather on many different parts of this Country, the RA team walk on the land of the Birpai, Gadigal, Darkinjung, Wadawurrung, Jagera, Turrbal, Whadjuk and Southern Yamatji peoples. We are committed to honouring the rich culture of the Aboriginal and Torres Strait Islander peoples of this Country, and the diversity and learning opportunities they provide us with. We extend our gratitude and respect to all Aboriginal and Torres Strait Islander peoples, and to all Elders past, present, and emerging, for their wisdom, their resilience, and for helping this Country to heal. Always was, always will be Aboriginal land.



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Artworks © Celeste Josephine Art, 2020, 2021

