



Reframing Autism

2021-2022 Financial Year

Annual Report



reframing
AUTISM

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Message from the CEO

It was with a profound sense of déjà vu that I began preparing Reframing Autism's 2022 Annual Report. When I composed the Annual Report in 2021, I had a sense of cautious hope that 2022 would bring some easing of the physical, mental and emotional burden of the COVID-19 pandemic. I hoped that, globally, we might experience a reprieve from what seemed like a veritable onslaught of difficulties throughout 2020 and 2021.

Yet, as we come to the end of 2022, and although the restrictions relating to the COVID-19 crisis have eased considerably, we have lived through yet another year filled with significant global challenges. From the war in Ukraine, to repeated natural disasters in Australia and abroad, to the cost-of-living crisis, 2022 has thrown all manner of challenges at us as a global community. We must acknowledge that some of these, like cost-of-living, will drastically and unfairly impact our Autistic community, of which so many already live at or below poverty. And the long-term mental and physical health implications of the pandemic and its associated restrictions will no doubt continue to unfold for Autistic individuals, who were disproportionately negatively affected both mentally and physically by the virus.

So, as I wrote last year, just as 2021 was not a panacea for 2020, neither has 2022 been one for 2021. We are, it seems, living in a period of extreme uncertainty and distress, and we probably need to accept that this reality is one that may stay with us for a considerable period to come.

For not-for-profit organisations, like Reframing Autism, that reality makes our *raison d'être* more compelling and imperative. Now, more than ever, we need organisations and people who are committed to building the wellbeing and to protecting the rights of those who are vulnerable, marginalised, oppressed, and discriminated against. Because – whilst arguably most people are struggling as 2022 comes to a close – minorities are struggling more, and in more ways.

So, I want to take this opportunity to share with you how Reframing Autism as an organisation is working towards its mission of fostering Autistic wellbeing, validating and valuing Autistic experiential knowledge, challenging the pervasive narratives about Autism that seek to oppress, marginalise and exclude us, and upholding Autistic rights.



Our all-Autistic operations team has been tireless in its efforts to showcase diverse Autistic voices and offer opportunities for new voices to contribute to our organisation. We have worked hard to educate our Autistic neurokindred and our allies towards wellbeing. We continue to contribute to a growing body of Autistic-informed, co-produced research. And our fully neurodivergent Board has continued to lead Reframing Autism with deep commitment combined with experiential and stakeholder expertise.

It has been my honour and pleasure to head Reframing Autism again this year as its CEO, but it is not a role I could perform without the incredible devotion, support and wisdom of my colleagues both within Reframing Autism, and outside of it. I am so lucky to have the privilege of working with such a committed and talented team, and to be able to call on the incredible breadth of expertise and passion that the Autistic community offers.

It is thus with considerable pride that I invite you to read this Annual Report, which reflects upon Reframing Autism's activities for the 2021-2022 financial year.

Melanie Heyworth

Melanie Heyworth
CEO & Founder





Message from the Chairperson

I wish to begin this message by showing my sincere thanks to my predecessor and founding chairperson, Kathy Isaacs, whose tireless efforts in leading the board set the foundations for Reframing Autism to be the organisation it is today. Their work has made ours much easier, and for this I am grateful and humbled to be their successor.

We continue to operate in a volatile and uncertain environment. While there remain global crises and challenges that pose generational challenges, at home the past year has seen significant upheavals that have impacted how the board has guided the organisation. Of most note are the outcomes of Federal and state elections and the implications for policies that affect the lives and livelihoods of Autistic people and families. Fortunately, many of these policy directions appear to be supportive, though it will require the vigilance of our board and staff to ensure that these supports are realised in practice. Moreover, the upcoming review of the National Disability Insurance Scheme provides a rare opportunity to enhance the availability and quality of supports for Autistic people, and we will be watching closely for opportunities to play a role in this conversation.

For these reasons, over the past year the board and staff have worked to build Reframing Autism into an organisation that can continue to deliver on its mission while being able to flexibly respond to changes both globally and locally. In practice, this has meant the formation of subcommittees that draw upon board members, staff and external expertise from our network to gather evidence and provide support to decision making. This includes ensuring that our operational risks are managed appropriately, and ensuring that we invest in our future financial stability. We have also continued to make a conscious effort to reflect the diversity of our stakeholders through our committees and staff, and to integrate considerations and implications of diverse lived experiences into our activities. This is already producing positive change in how we do what we do, and proving the value of diversity as a force for positive impact on society.

While this has seen a growth in our board and staff members, it is also worth acknowledging and thanking those members who left Reframing Autism in the past year. Their contributions have been immense, and have helped to make Reframing Autism the organisation it is today.



And Reframing Autism is an organisation with a growing national and international profile, and an emerging leader in the Autism and neurodiversity policy space. Our resources have been cited across a range of media articles, including by experts in the field. Moreover, our position in the research community has been reflected by the invitation to Mel Heyworth to deliver a keynote at the 2022 Australian Society for Autism Research conference, that drove home the importance of questioning the purpose and benefits of research from the outset and making the case for including people with lived-experience as equal partners in research delivery and translation to practice. These points reflect a broader conversation in the research space, and our activities prove that Reframing Autism are leading the way towards best practices.

I am optimistic that Reframing Autism is positioned to deliver even bigger things in 2023 and beyond. Through the hard work of the team, our reach and influence has extended into new domains, and our resources fill a key demand of the community for accessible research resources that can guide informed, evidence-based decision making. In 2023 our program of conferences and symposia will grow, along with our library of resources. Through this and our ongoing advocacy we plan to reach an even broader audience both in Australia and abroad. By investing in building our networks and our capacity to gently influence the discussion, we can make an even more positive impact on the lives of Autistic people, their families, and on society.

Gerard Atkinson

Gerard Atkinson
Chairperson





Education

“Change is the end result
of all true learning.”

— Leo Buscaglia

In summary, we

- Offered three on-demand, online workshops, for parents, allied health professionals, and teachers respectively;
- Convened two, one-day, single-stream online symposium on Autistic Flourishing: Acceptance, authenticity, autonomy, and on Autistic Relationships: Communication, community, connection;
- Offered a range of parent educational opportunities, including five, "in depth" masterclasses on topics like co-regulation and inclusive schooling;
- Presented two continuing professional development workshops on Autistic neurology and on Autistic experiences of mental health and wellbeing;
- Ran bespoke professional development workshops for four allied health organisations;
- Consulted on and presented at Women in Super's "Neurodiversity in the Workplace" event;
- Gave guest lectures to students in undergraduate and postgraduate tertiary programs, and
- Facilitated eight intakes of our online courses for parents, professionals and Autistic adults on Fostering Autistic Wellbeing.



Education in practice

In late 2021, Reframing Autism launched the first Certificate of Autistic Wellbeing. The Certificate is a free, facilitated, online course of learning that builds Autistic self-understanding and provides the tools to support Autistic individuals to self-advocate, as well as to advocate for their wider communities if they so choose. The Certificate is designed, produced, delivered and facilitated by an entirely Autistic team, centering Autistic lived experience as the expert voice, especially in discussions of specifically Autistic experiences of wellbeing.

Our original pilot iteration launched in September 2021 with a total of 18 participants. After this successful pilot, we then offered three more intakes for Autistics across the 2021-2022 financial year.

Excitingly, through the Certificate, we have fostered ongoing, formal relationships with a number of alumni from the Certificate, leading to further opportunities with Reframing Autism, including course facilitation and paid employment, resource development, and Board representation.

In total, we have supported 56 Autistics to engage with their wellbeing through increased self-knowledge over the 2021-2022 financial year. We are thrilled that the courses remain popular, with a substantial waitlist for each intake.

In addition to the Certificate for Autistics, at the beginning of 2022 we also launched the Certificate of Autistic Wellbeing in two new paid iterations: one for parents and families of Autistics, and one for professionals working with Autistics. Both courses have had two successful intakes each over the 2021-2022 financial year. Thanks to our Department of Social Services grant, we have also been able to offer scholarships to Autistic parents and professionals taking these iterations, and full and partial scholarships to some non-autistic parent participants. Subsidising families to undertake our courses is an important way to establish educational equity and to further support our Autistic community.

We look forward to continuing to iterate and develop our Autistic Wellbeing courses in 2022-23, and to finding new and innovative ways to grow the advocacy skills and self-development of our community and our allies.





Resources

“ What we find, changes
who we become. ”

— Peter Morville

In summary, we produced

- Five "Easy Read" resources, on topics like double empathy, therapies, social motivation, LGBTQIA+ rights, and communication;
- One position statement on Autistic communication, and an open letter to the Lancet Commission of the future of core and clinical research in Autism;
- Seventeen Autistic-authored blogs, most of which were sourced from outside the Reframing Autism team;
- Six podcasts in our Amplified series, showcasing Autistic voices from around Australia and the world;
- Nine webinars, freely available on our YouTube channel;
- Six tip sheets for the community, including on neurodiversity-affirming language, practical strategies for parenting Autistic-LGBTQIA+ young people, transitioning to tertiary education, and preparing for COVID-19;
- Three research summaries, written in an accessible format to connect the Autistic and autism communities with important research about us, and
- Key resources on parenting and education translated into different languages, including into Arabic, Mandarin, Vietnamese, Spanish, Greek, Italian, Traditional Chinese, Tagalog, Hindi and Punjabi.



Resources in practice

As an organisation that combines Autistic lived experience and research in our work, we know how important research is. But when research fails to reach those who might benefit most from it – the Autistic and autism communities in the case of Autism science – it will likely also fail in its mission to impact positively the lives of Autistics.

So, in 2021, Reframing Autism began publishing research summaries, which synthesise and translate academic learnings into easily understandable language, so that Autistics and our allies outside the research space can have access to vital information about ourselves. This act of “knowledge translation” helps to bridge the gap between the research community and the Autistic community and to ensure that research can have a functional real-world impact on the people it serves.

During 2021-22, Reframing Autism released three research summaries:

- “Just Ask Me”: The Importance of Respectful Relationships Within Schools;
- “It just fits my needs better”: Autistic students and parents’ experiences of learning from home during the early phase of the COVID-19 pandemic, and
- “I’m Proud to be a Little Bit Different”: The Effects of Autistic Individuals’ Perceptions of Autism and Autism Social Identity on Their Collective Self-esteem.

Our research summaries explain why a study was done, what was found, why the findings are important to the Autistic community, and offer suggestions for putting learnings into practice. Research summaries also often include options to expand learning or links to other resources, allowing readers the chance to dive deeper into a particular topic of interest. Some of our research summaries have also been translated into Easy Read format to reach a wider audience.

Ensuring research knowledge reaches Autistics directly is an important focus for Reframing Autism. We will continue to produce research summaries to make sure the Autistic community has access to current research in a more accessible way.



Diversity & representation

“In diversity, there is beauty and there is strength.”

— Maya Angelou

In summary, we

- Published three of our key resources in languages other than English;
- Hired an Accessibility and Inclusion Lead to the Reframing Autism team to launch and run our Intersectional Advisory Committee;
- Focused Season Two of our podcast series, Amplified: Autistics in Conversation with Reframing Autism, on featuring new and diverse Autistic voices, including those who are non-speaking;
- Worked with Autistic individuals outside our Reframing Autism team to produce lived experience blogs and testimonines, including ten Autistics who were completely new to Reframing Autism, and
- Published five of our key resources into "Easy Read" format to increase accessibility for our community.



Diversity & representation in practice

Reframing Autism remains focused on ensuring that our work can reach anyone who might need it, and we are committed to removing potential barriers to engagement with our work. Thus, in the 2021-2022 financial year, we published resources in other languages, continued providing information in audio, image and video formats as well as written resources, and commissioned a series of Easy Read translations for our position statements and research summaries.

We are also working on diversifying the voices in the Autism space and providing pathways to advocacy and contribution for our community. In 2021-22, we published resources from voices who were new to Reframing Autism, including ten blogs and two podcasts. For many of these individuals, their contribution to Reframing Autism was an early step in developing skills and confidence to share their journeys or to build an advocacy career.

We are actively continuing to provide a variety of different opportunities and ways for Autistics to contribute to our work. All contributions to resource development are paid, and we are proud to be offering paid opportunities to Autistic creators as often as we can.

In addition, we are committed to ensuring we have diverse voices guiding our work and priorities into the future. The Intersectional Advisory Committee (IAC) is a proposed new addition to our organisation, creating more space for diverse representation and feedback without the full commitments and responsibilities of joining the Board of Directors. The IAC will add another layer of accountability to our organisation and help us to reach and support diverse Autistic people with our work. Our Inclusion and Accessibility Lead started with Reframing Autism in June 2022 and planning for the IAC is well underway. The first Intersectional Advisory Committee meeting will commence in late 2022.



Research

“Research must continue to be the centrepiece of intellectual life, and our commitment to research must grow, because our problems are growing.”

— Ernest L. Boyer

In summary, members of our team

Contributed to the following peer-reviewed research articles, published in the 2021-2022 FY:

- Heyworth, M., Brett, S., den Houting, J., Magiati, I., Steward, R., Urbanowicz, A., Stears, M., & Pellicano, E. (2022). “I’m the family ringmaster and juggler”: Autistic parents’ experiences of parenting during the COVID-19 pandemic. *Autism in Adulthood*. doi: 10.1089/aut.2021.0097
- Heyworth, M., Chan, T., & Lawson, W. (2022). Perspective: Presuming autistic communication competence and reframing facilitated communication. *Frontiers in Psychology*. doi: 10.3389/fpsyg.2022.864991
- Heyworth, M., Brett, S., den Houting, J., Magiati, I., Steward, R., Urbanowicz, A., Stears, M., & Pellicano, E. (2021). “It just fits my needs better”: Autistic students and parents’ experiences of learning from home during COVID-19. *Autism & Developmental Language Impairments*. doi: 10.1177/23969415211057681
- Lilley, R., Lawson, W., Hall, G., Mahoney, J., Clapham, H., Heyworth, M., Arnold, S. C., Trollor, J. N., Yudell, M., & Pellicano, E. (2021). “A way to be me”: Autobiographical reflections of late-diagnosed autistic adults. *Autism*. doi: 10.1177/13623613211050694

Contributed to the following research projects, continued or begun in the 2021-2022 FY:

- MRFF (NHMRC) Enhancing Quality of Life through an Early Intervention co-developed with the autistic community (E-QoL-ITY) (Griffith University)
- Parenting Autistic children (PhD) (Macquarie University)
- The impact of the COVID-19 pandemic on Autistic individuals and their families (Macquarie University)
- Culture and connection: Building strong home-school partnerships with culturally and linguistically diverse families of Autistic children (Macquarie University & Positive Partnerships)
- Strengthening partnerships: Autistic parents' experiences with Australia's schools (Macquarie University & Positive Partnerships)

Presented or co-presented:

- A keynote presentation at ARCAP's Innovations in Autism Practice with Prof Liz Pellicano
- Posters at ARCAP's Innovations in Autism Practice, and at the 2022 INSAR Annual Conference
- A keynote presentation for Autism NZ's Autism Education Event, 2022



Research in practice

Reframing Autism is committed to furthering the aims of inclusive research that is genuinely co-produced with the Autistic community, and which acknowledges our community as the clear beneficiaries of knowledge production and translation. We have thus offered our time and expertise to various research projects as co-researchers, collaborators, partners and consultants to ensure that Autistic voices are represented across the research lifecycle and to inform all elements of research to best serve our community.

Typically, Autism science has been designed and conducted without any significant input from Autistic people and their allies, although encouragingly this is beginning to change. At Reframing Autism, we urge every researcher with whom we work to contribute to that change. We challenge them to fulfil the basic mission of Autism research, which is to benefit the Autistic community and foster our quality of life. We support them to consider how the research knowledge they have, will be translated to the communities who are the immediate and practical beneficiaries of what they discover.

It is through research that is co-produced with and for the Autistic community that we will effect the greatest change for Autistic wellbeing and quality of life across the lifespan. The Reframing Autism team, then, are challenging the research status quo paradigm by positioning Autistic voices not just as passive participants in or subjects of research, but as experts whose experiential knowledge brings depth, rigour, practicality, accessibility and relevance to Autism science.

We are building relationships with Australian Universities and Autism researchers to ensure that Autistic individuals, regardless of communication and support needs, are offered genuine power in the research dynamic. We look forward to continuing our research collaborations and to working with more researchers as new opportunities emerge.



Impact report

2021-2022 FY highlights and impact

Worked with nearly
100
Autistic contributors
since inception



Employed a
fully Autistic
operations team



Provided educational opportunities to over

1,300

Autistic individuals,
and their parents and professional allies

Over

78,000

followers across social media platforms



Contracted and paid
Autistic contributors on

all
projects



Collaborated on



4

research projects

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 the 2021-2022 financial year, but there is still much work to be done.



Financial highlights

As an Autistic-led organisation, we aim to ensure that Autistic people are centered in our work and are paid for their financial contributions. With that idea at the heart of what we do, 75% of our total costs were paid to Autistics in the 2021-2022 financial year. This was a mix of Autistic staff, Autistic contributors and professional fees.

As we continue to improve our operational efficiencies, we managed to spend 89% of our overall costs in the 2021-2022 financial year directly on programs benefitting the Autistic community. 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.

**75% of total
costs paid to
Autistics**

During this year, 79% 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 19% 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 2%.



Financial statements



Statement of Profit or Loss for the year ended 30 June 2022

	2022 \$	2021 \$
Revenue	609,852	520,055
Other income	1,179	1,725
Amortisation & depreciation expense	(2,495)	(1,919)
Bank fees & charges	(318)	(245)
Employment expenses	(389,884)	(297,423)
Insurance expenses	(6,635)	(5,692)
Technology expenses	(60,556)	(17,401)
Other expenses	(97,764)	(143,612)
Net surplus for the year	53,379	55,488



Financial statements

Statement of Financial Position as at 30 June 2022

	2022 \$	2021 \$
Assets		
Current assets		
Cash & cash equivalents	502,671	61,242
Trade & other receivables	709	3,070
Other current assets	6,079	316,277
Total current assets	<u>509,459</u>	<u>380,589</u>
Non-current assets		
Property, plant and equipment	2,663	5,055
Total current assets	<u>2,663</u>	<u>5,055</u>
Total assets	<u>512,122</u>	<u>385,644</u>
Liabilities		
Current liabilities		
Trade & other payables	12,376	8,394
Provisions	19,060	16,341
Other liabilities	370,138	303,740
Total current liabilities	<u>401,574</u>	<u>328,475</u>
Total liabilities	<u>401,574</u>	<u>328,475</u>
Net assets	<u>110,548</u>	<u>57,169</u>
Equity		
Retained surpluses	110,548	57,169
Total equity	<u>110,548</u>	<u>57,169</u>





Thank you for your exceptional work. Of all the people/organisations I follow, I am most grateful for yours. Your ability to be outhentic, intellectually rigorous and deeply respectfully is a real feat. It is evident there is a high standard of research and knowledge that manages to be communicated in everyday language. Lived experience and academic understanding are intertwined and there seems to be a healthy critical reflection around it all. I am truly impressed with what you are doing and hope that more people can learn through your work.

(Parent of Autistic children)



I cherish Reframing Autism and wish you continued growth and success.

(Suspected Autistic parent of Autistic children)



Feedback



You are such a valuable resource and I feel heard through what you share. Thank you.

(Autistic professional, researcher and parent to Autistic children)



Reframing Autism is a beautifully presented platform to educate and support a wide sector of the Autistic community and allies. I can't speak highly enough of the organisation. It has helped me become a better educator.

(Suspected Autistic professional)





Feedback

“ I think the work you are doing is really wonderful and I'm so glad that I found Reframing Autism, you guys are such an amazing resource for parents like me who want to learn how to be the best parents we can for our amazing kids and how to help them truly and authentically thrive.
(Education professional and parent of Autistic child) ”

“ Just thank you. Thank you for letting me be a part of the Autistic Wellbeing Course (for Autistics) and for giving me a space where I feel affirmed and validated.
(Autistic parent and health professional) ”

“ When I took the Autistic Wellbeing course, I was struggling with how I viewed myself and my future due to certain challenges related to being Autistic. By the end of the course I was in a much, much better headspace and am still maintaining that improved perspective months later. I credit the course for a big part of that, as it gave me space to explore other perspectives and viewpoints.
(Autistic person) ”

“ Thank you for all that you do. Reframing Autism is so important for people to learn about Autism from Autistic people.
(Parent of Autistic child or young person) ”



Acknowledgements



Our team

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Board of Directors

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Maria Herminia Graterol
Dr Melanie Heyworth
Dr Justine Noble
Mikala Sedgwick

Our sponsorship partners

My Care Space
AutismConnect (AMAZE)
The A List
Mable
ANZ
Autism Camp Australia

Reforming 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.





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

— Nelson Mandela



Questions, comments, or feedback on Reframing Autism's Annual Report can be
forwarded to: info@reframingautism.org.au

Reframing Autism, PO Box 444, St Leonards NSW 1590

www.reframingautism.org.au



reframing AUTISM

respect • accept • embrace • empower

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, Cammeraygal, Wattamattagal, Wadawurrung, Wajuk, Amangu and Bunurong 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.

