

# reframing AUTISM ANNUAL REPORT Fiscal Year 2020

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# WELCOME TO OUR 2020 ANNUAL REPORT

# At Reframing Autism, our mission is simple: respect, accept, embrace and empower the Autistic community.

Since our inception as an independent organisation in mid-2019, we have made significant progress in establishing a strong following of Autistic individuals and their families and allies to help us in achieving our mission.

This progress was made possible by two National Disability Insurance Scheme grants under the Information, Linkages and Capacity Building fund for emerging Disabled Persons Organisations and for Individual Capacity Building, and by the support of Plumtree Children's Services, under whose careful guidance Reframing Autism was auspiced.

We are delighted to share with you through our Annual Report some of our stories of change and impact.

We hope you will be inspired to share the work of Reframing Autism and to become involved in our movement for social change.

magente

Dr Melanie Heyworth CEO & Founder



Kathy Isaacs

Kathy Isaacs Chairperson

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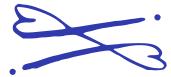
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# 1.Vision, mission, objectives, values



# Our vision

Reframing Autism aims to create a world in which the Autistic community is supported by families and allies to achieve genuine acceptance, inclusion, and active citizenship, and in which Autistic culture and identity are celebrated and nurtured.



Reframing Autism is a company run by and for Autistic people, and for their families and allies. We combine capacity-building and leadership development with education, research, resource development, mentoring, and support to strengthen the Autistic community. We also promote a united community, bridging the divisive gap between the Autistic community (those identified or who self-identify as Autistic) and the 'Autism' community (the broader nonautistic community with a connection to Autism).

Through Reframing Autism, Autistic people, and non-autistic families and allies of the Autistic community, come together to understand Autism. We promote equity and acceptance. Our vision and goals align with the Australian National Disability Strategy 2010–2020 and the UN Convention on the Rights of Persons with Disabilities.

Reframing Autism builds hope in the Autistic community by fostering great expectations for a rewarding life grounded in the civil, political and social participation of Autistic people. Reframing Autism also builds hope in the families and allies of Autistic people, moving beyond the narrative of causes, cures and interventions and offering away to embrace the Autistic community.

Working within the neurodiversity movement, Reframing Autism provides both support and education. Through Reframing Autism, families and allies learn from Autistic people of all ages, to establish inclusion founded in reciprocal respect and a mutually supportive community. It encourages environments in which Autistic individuals can live authentically, and it builds the capacity of families, allies and Autistic people themselves to be leaders and change agents.



# Our mission

At Reframing Autism, we want to **change the narrative** to fit a strengths-based, neurodiversity view.

Ultimately, our goal is to improve Autistic mental wellbeing.

We want the Autistic community to be included, embraced and valued.

We want Autistic people to be **active** citizens.

We nurture Autistic identity and culture.

And we celebrate diversity in all its forms.



# Our charitable objectives

Reframing Autism is a Health Promotion Charity, and its activities are intended to improve the current bleak mental health profile of the Autistic community, caused by lifelong exposure to discrimination, stigmatisation and exclusion.

Our objectives are to:

- Empower Autistic individuals to be leaders for their community.
- Support families and allies to meet the needs of Autistic people by embracing the principles of acceptance, respect, and neurodiversity.
- Provide the broad community, especially the families and allies of Autistic individuals, access to Autistic lived experiences and perspectives through education and information.
- Provide opportunities to include underrepresented and marginalised Autistic individuals in Reframing Autism's governance, educational framework, and in participatory research.
- Bring a national focus to the nature, role and importance of parenting Autistic children with acceptance and respect, and to provide Autistic representation in appropriate policy making and funding bodies.
- Enhance the capability of families through training, workshops, and mentoring.
- Provide a national forum for communicating and sharing information, philosophies, and practices that are respectful of Autistic neurology.
- Provide accessible and informative resources for Autistic individuals, and their families and allies.
- Undertake evaluation and research, to ensure Reframing Autism continues to produce quality outcomes and transferability.
- Establish a partnership ecosystem with relevant peak representative bodies nationally.



# Our values



**Reframing** is about changing the frame through which we view Autism. Reframing isn't about changing Autism. It isn't about changing Autistic people. Reframing is about changing the frame through which we view Autism. It's about

losing the stereotypes. And the stigmas. And the prejudice. It's about changing our lens so that we see the strength in Autism. And the value. And the beauty. Reframing means acceptance, inclusion, equity and employment. And that means that we are free to be our Autistic selves. It means that people don't just think that our Autistic way of being is



acceptable or tolerable. It means they celebrate it as awesome.

### The frame we've chosen to see Autism through is called **Neurodiversity**.



The infinity symbol that forms our logo is the symbol of neurodiversity. Neurodiversity simply means we see Autism as valuable, worthy and natural. It means we think of brain differences as necessary and beneficial. We have used a repeated infinity symbol to make our special knotwork icon. The repeated infinity speaks to the infinite diversity of humanity. t also speaks to the interconnectedness of that diversity. We rely on diversity to make the world the amazing place it is.

We also have a kaleidoscope pattern of colours in our infinity logo. When you look through a kaleidoscope, you see gorgeous colours and shifting patterns. What you see might be unexpected. It might be different each time you view it. But it is always beautiful. We think that's a bit like Autism. Unexpected. Different. Beautiful.

Reframing Autism is special. We are run by autistic people, and we employ and contract Autistic people. We also bring Autistic people, and non-autistic families and allies of the Autistic community, together. Autistic people lead by sharing their lived experiences and their unique knowledge and gifts. Together we grow to understand Autism and neurodiversity. Together we promote equity and acceptance.





We believe that if we have great expectations for a rewarding life, we will build optimism and hope. We have great expectations that the Autistic community can be self-determined, resilient, active citizens. That Autism will be valued, esteemed and respected. That families and allies of the Autistic community will live better lives by embracing the Autistic community. And that our families will learn with us to build a supportive world that appreciates Autism in all its guises.

# Our guiding principles

At Reframing Autism we...

Respect Accept EMBRACE Empower through

gentle influence



# 2. Our story



# Our story

Dr Melanie Heyworth founded Reframing Autism in 2017. At the time, she was working as a peer facilitator for an early childhood intervention organisation, Plumtree Children's Services, in Marrickville in Sydney's Inner West.

In her work with Plumtree, Melanie recognised that many parents of newly identified Autistic children could benefit from hearing from Autistic adults directly and needed to be able to access the Autistic community.

The Council for Intellectual Disability (NSW) provided funding to launch Reframing Autism in the form of a 'Peers Creating Change' Grant. The first Reframing Autism events were workshops aimed to support those Plumtree families with Autistic children. Plumtree provided the workshop venue and offered childcare so families could come along easily.

Reframing Autism's first workshop had eight families. It grew quickly to fifty families. Then, in 2019, the NDIS gave Reframing Autism a grant so that we could become an independent organisation.

Plumtree continued to help and guide us through this transition phase to independence by auspicing us for the grant, under the expert guidance of Plumtree CEO, Sylvana Mahmic, and Project Sponsor, Margie O'Tarpey. Our successes with this funding were evidenced by the news in late 2019 that we had won another NDIS grant, this time for \$1,350,000 for three years.

We couldn't have achieved what we have achieved at Reframing Autism without Plumtree's initial belief and their ongoing support. Melanie and the Reframing Autism team are so grateful to Plumtree for believing in her vision and supporting it to grow. We are also deeply grateful for the NDIS grants that have allowed Reframing Autism to flourish and grow.



# **REFRAMING AUTISM**

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# EARLY 2019

Reframing Autism receives \$118,000 funding from the NDIS to expand its activities and to become an independent charity. We have one employee and many dedicated volunteers.

# LATE 2019

Reframing Autism receives a further \$1.35 million grant from the NDIS after the successes of its initial funding.

# 2020

For much of 2020, Reframing Autism operates both NDIS grants concurrently. We expand to a team of three paid employees, supported by volunteers.

# PRESENT

We now have six employees, and contract many others to support Reframing Autism's work. We are recognised internationally and have a global following of around 15,000.

# (r)evolution

# A brief history of our

Plumtree, facilitated by Melanie Heyworth, with 8 families in attendance and funded by a small CID NSW Peers Creating Change Grant.

# 2018

Quarterly groups run at Plumtree, and Reframing Autism hosts esteemed guests like Michelle Swan and Yenn Purkis to 50 families, with a waitlist for attendance.

> Reframing Autism's first group runs at

**LATE 2017** 

# Families & allies: building connections

In the past year, Reframing Autism has undertaken the vital business of positioning itself in the Australian Autistic advocacy space, and of understanding what is unique about Reframing Autism in the Australian context.

Reframing Autism has defined one of its core objectives as bringing together the Autistic and autism communities within a culture of empathy and gentle influence. In essence, at Reframing Autism we see parents and allies as our necessary partners in achieving social change, rather than identifying those families and allies as targets of our advocacy. This distinction is more than mere semantics. Social change can, we believe, only be achieved when families and allies are active participants in changing the narrative about Autism.

We know that Autistic children are damaged when they are raised in homes that don't understand or respect Autism. So, our rationale for working with families is simple: it will make the greatest difference to Autistic children, and it will make our Autistic children happier, safer, more resilient, accepted adults when they are no longer in living their childhood home.

There are other compelling reasons too. The Autistic community is experiencing a mental health crisis, across our lifespans. Autistic adults and children alike are reporting profoundly unacceptable rates of anxiety, depression, PTSS and PTSD, and suicidality. We also know that 'adaptive morphing', or what most of us call masking, is a contributing factor to mental illness.

And it isn't surprising: children internalise messages from their parents (whether consciously intended or not) that they are not enough, that they are broken, that they are deficient or wrong as they are, as their authentic Autistic selves. They sacrifice their sense of 'intactness' – the intrinsic sense of who they are – to please their parents. And they suffer deeply not only because of the masking, but because of the internalised ableism that often accompanies it.

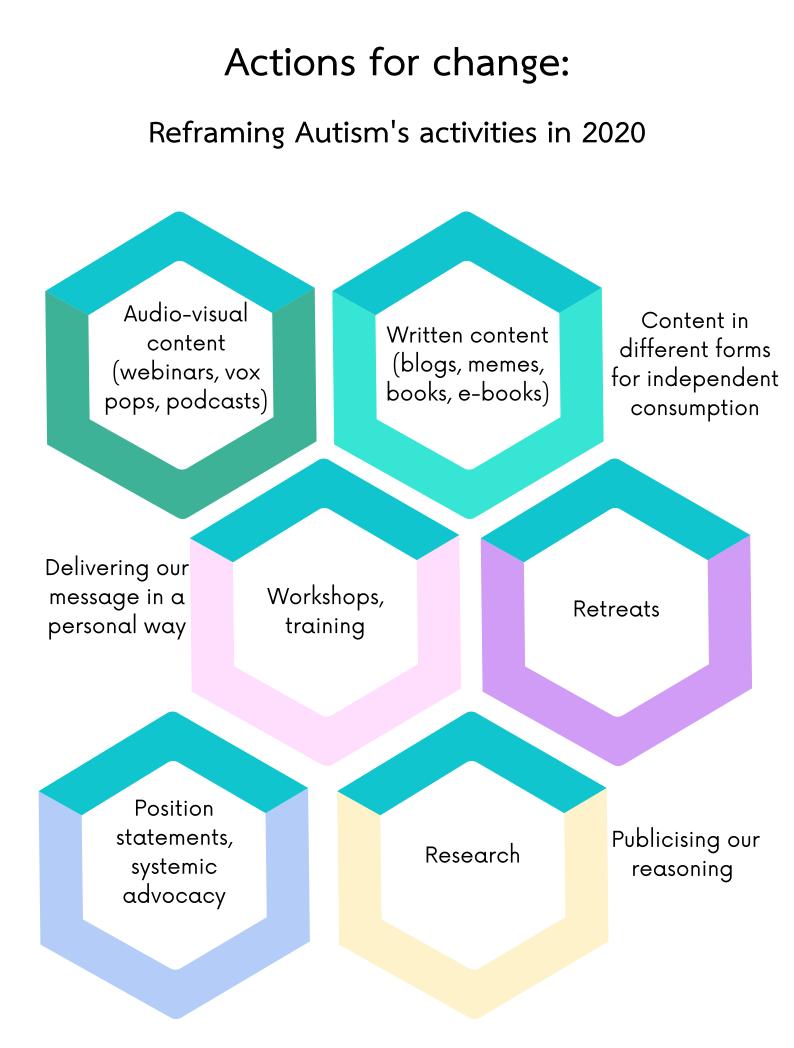
So, at Reframing Autism, we acknowledge the fundamental truth that the Autistic community needs families. We need them to understand Autistic neurology, to respect it, and to embrace it. By bringing families and allies along with us on the journey to acceptance, we are able to influence intimately not only the day-to-day experiences of Autistic children of all ages, but also the messaging that families and professionals take into the world, be that in education, allied , or the broader community. When families and allies are amplifying Autistic voices, rather than speaking over them, we have the best opportunity for affecting genuine change.

It is unfortunate that, very often, many in the autism community feel 'attacked' by militant

activism, and in response they reject Autistic voices and messages of acceptance and respect. Whilst Reframing Autism usually endorses the content of such activism, we have determined that the best way of encouraging those in the autism community to listen to the underlying message of it, is to adopt the frame of 'gentle influence'. That means that we first try and find commonalities with our audiences so that we begin from a point of empathy. For families, for example, we begin from the assumption that we all want the best for our Autistic children, and that the motivation for our decisions is grounded in the best interests of the child. This position doesn't meant that we sacrifice our principles to ensure families and allies are not uncomfortable. Rather, we understand that discomfort need not be combative, or antagonistic, or adversarial. Instead, we see our mission as a gentle and empathetic one. We maintain our principles, and we educate through quiet influence. Thus, at Reframing Autism, it is our culture to work *with* families and to bring them into the community of genuine allies.

# 3. Activities





## How we supported our communities in 2020

Reframing Autism aims to build the capacity of the Autistic and Autism communities to be leaders for positive social change.

We deliver clear and consistent messages of respect, acceptance, empowerment, neurodiversity, and citizenship.

Our programs and resources are co-designed with both the Autistic and Autism communities and are based on experiential knowledge, evidence, and need. We offer families alternative to therapies and interventions through sharing Autistic insights and experiences.

# Educational opportunities Information & resources

Reframing Autism hosts online webinars and live workshops that offer an opportunity for families and Autistic individuals to learn from Autistic leaders.

Our educational program covers topics that increase families' capacity to understand what their child's Autism means, how their child might experience Autism, how to create connections with the Autistic and Autism communities, and other relevant issues. Reframing Autism has developed information and resources to assist the Autistic community and their families to understand Autism. These resources include blog posts, tip sheets, videos, books (both traditional and e-books), infographics, and content for social media, like memes.

All resources are composed, filmed, produced, illustrated, designed, or otherwise published by Autistic individuals themselves.



# Research & advocacy

Reframing Autism participates in respectful, co-produced research, which has the potential to make positive contributions to the lives of Autistic individuals.

Our CEO, Dr Melanie Heyworth, represents Reframing Autism on the Australian Autism Research Council (AARC) and the Aspect Research Centre for Autism Practice (ARCAP), among other advisory boards and research councils.

Reframing Autism was a key participant in a collaborative, co-produced research project on the experiences of Autistic individuals and their families during COVID-19 restrictions and lockdown. This research will guide future policy.

Reframing Autism has also been invited to be an ARC Linkage Grant industry partner in a University of Wollongong led project on Autistic identity and culture, and to work with Macquarie University and Positive Partnerships on researching experiences of Autistic parents of Autistic children in parent-school partnerships.

# Retreats & symposia

In late September 2020, Reframing Autism offered its inaugural Parent Retreat, aimed at educating parents of newly identified Autistic children in Autism, neurodiversity, and respectful parenting techniques.

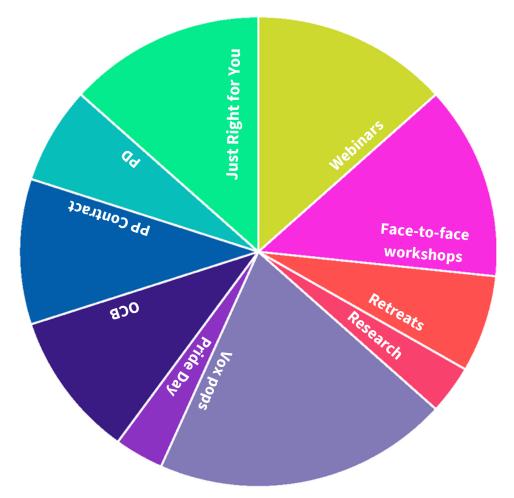
The Retreat, which ran for two nights and two days, was a resounding success, with 8 participants (6 mothers, 1 father and 1 support worker) and 3 Autistic facilitators.

Unfortunately, due to COVID-19 restrictions, we were unable to hold a 2020 symposium. Our next symposium is scheduled for Adelaide to coincide with Autistic Pride Day on June 18 on the topic of Gender, Sexuality and Autism.

# reframing AUTISM ANNUAL REPORT 2020 Summary output



# The last year's activities in summary:



In 2020, despite COVID-19 restrictions which made live events challenging, Reframing Autism hosted a live Masterclass on Autism & Anxiety by Dr Jac den Houting. We are currently planning for a workshop aimed at birth workers supporting pregnant Autistic women for late November. We also ran our inaugural Parent Retreat at Yanada in St Albans, in the Hawkesbury region of NSW.

We participated in research, especially a collaborative international study of the impacts of COVID-19 lockdown on Autistic people and their families, from which we have published a comprehensive report and will present a keynote paper at ASfAR in December.

We launched a webinar series by Jessica Harrison on Autistic empathy.

We produced a substantial series of vox pop videos featuring new and established Autistic advocates from around the world speaking on Autistic wellbeing, thriving, passions and stimming in response to a need in the community during the COVID crisis.

We wrote and published an acclaimed picture book, *Just Right for You*, illustrated by young Autistic artist, I Am Cadence.

We celebrated Autistic Pride Day on 18 June with contributions written by our Autistic followers made into a beautiful video produced by Sophie Ralston, and an e-book illustrated by Autistic designer, Mandar Nelson.

We participated in organisational capacity building (OCB) activities such strategic planning. And the team was offered website accessibility, accessible information, key word sign, non-electronic communication aids, disability awareness training, and other key professional development. We accepted a significant contract with Positive Partnerships to produce new educational content for their website and online programs.

# Viral memes

Stimming is Autistic body language. It is an equally valid form of self-expression and communication as non-autistic body language.



What professionals might term "rigidity" or "inflexibility" is, in all likelihood, an Autistic person's attempt to manage a chaotic world through controlling what is controllable. © Reframing Autism, 2019.

© Reframing Autism, 2020.

If you accept that your own ability to function fluctuates depending on variables like sleep, health, or environment, then you accept that Autistic functioning can fluctuate too.

#NoFunctioningLabels

© Reframing Autism, 2020.

*Play.* Verb: "to engage in an activity for enjoyment or recreation". Don't let anyone tell you that your child's play is inappropriate or non-functional. *Play is play.*  There is no developmental window of opportunity. Autistic children continue to grow, learn and mature across their lives, just as non-autistic children do.



Autistic children need Autistic adult role models. They need Autistic adults who are "out and proud" about their Autism.

Contrary to most stereotypes, orthogonal thinking - making unusual connections to come to unique and genuinely new insights - is one of the

hallmark characteristics of the Autistic brain.



© Reframing Autism, 2020.

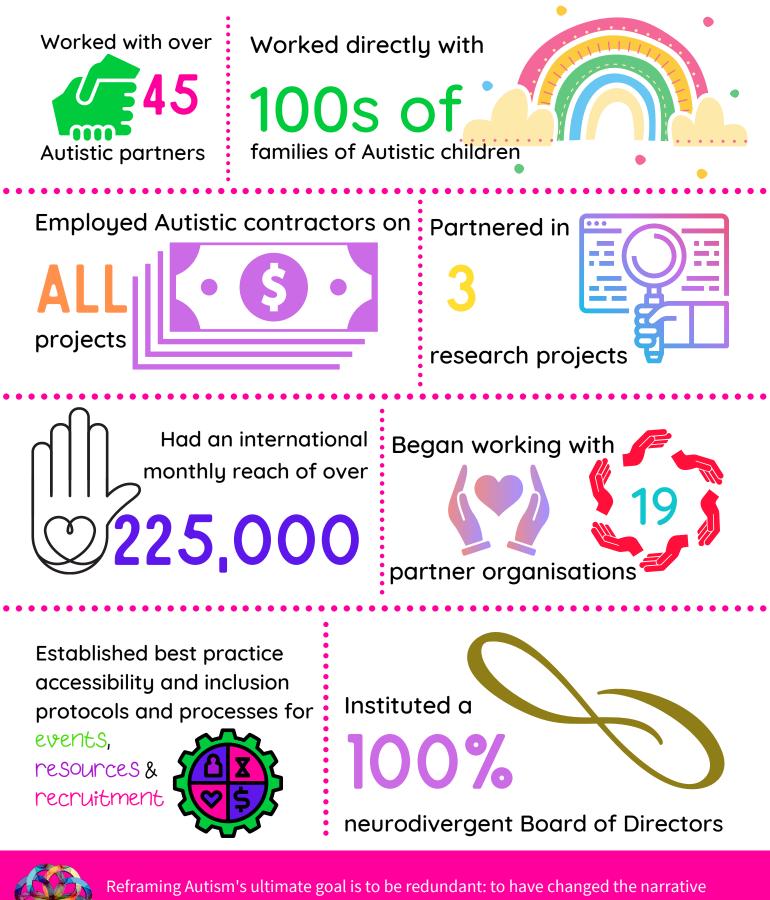
We don't, as Autistics, have 'special' needs. We just have human needs. Because different needs are normal, because different is normal.

# 4. Impact and engagement



# 2020 Impact report

Yearly highlights and impact





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 2020, but there is still much work to be done.

# reframing AUTISM ANNUAL REPORT 2020 Summary engagement



Facebook followers: 15,000 Monthly post reach: 150,000



Website subscribers: 600



YouTube subscribers: 474 Video views: 13,000



Instagram followers: 1,600



Attendees at live events: 68



Autistic collaborators: 49



# Audience feedback

99

"I feel so lucky to have come across your page and really blessed to have met you and to be able to learn from your knowledge and experience."

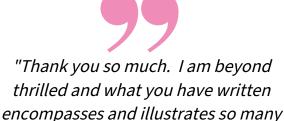


"I just wanted to thank you for all you share - it's been enlightening for me to read perspective[s] from the autistic community so we can best support our son. Thank you!"



"Thank you so much for your response. I really appreciate it. It helps so much knowing I can "speak" to someone who understands. There are some really helpful suggestions and thoughts here that I will consider and take on board."





important points."

"I wanted to say a BIG HELLO and provide a virtual hug to show my excite[ment] and joy that the organisation has launched and gotten of the ground. We so need

it here in Sydney and NSW."

99

"Thank you for listening and caring."

# Retreat feedback



"I am beyond grateful for being able to be a part of this experience... I came to the retreat feeling isolated and alone... I have not only found support and friendship but also a wealth of knowledge whether it be valid for my children or helping me understand others. ... I plan to embrace my children for who they are, for their interests and passions and learn to reevaluate and understand the perceived 'negative' behaviours from a different perspective. I am now aware of how much the confines of society have affected my interactions and reactions with my children and I now know it is OK to go against society norms and indeed I will take every appropriate opportunity going forward to help educate those around me to embrace the autistic community and my children."

*"I feel proud of my child being Autistic. You have reframed Autism for me."* 



"This retreat has been life changing for us as parents. I feel like I have seen through a window into our daughter's world for the first time. I know it will benefit her and us for years to come. Thanks!"

# Praise for Just Right for You from the



"Today we received our copy. It is a gorgeous book & brought tears to my eyes when reading it.





Got my copy of this today. What a lovely, positive, affirming book. It's wonderful. "AUsome validation for autistic individuals and an AUthentic opportunity for others to learn (Autism Level UP!)"

*"Grabbed a copy. My kids love books. I'm excited it's a book they can identify with."* 

*"A beautifully illustrated story of diversity and acceptance (Julia Hay of Julia's Place)"*  *"We got our copy today and love it! So happy my Autistic daughter has this positive book!"*  "It made me feel fortunate to parent autistic children in a time when autistic voices are heard, published, and celebrated. It made me feel even more grateful that I can introduce autism to my kids in this loving, natural way. (Not an Autism Mom)"

# 5. Financials (FY 2019-2020)



# Where did our funds come from?

In the 2019-2020 financial year the vast majority of Reframing Autism's income derived from the NDIS ILC DPFO grant (total grant amount of \$118,000 plus GST) and from the NDIS ILC ICB grant (total grant amount of \$1,350,000 plus GST). As both grants cross multiple fiscal years, revenue from the grants was recognised in line with meeting the conditions of the grant, which approximates the expenses.

The DPFO grant was auspiced by Plumtree and therefore was recorded separately to the ICB grant and all other activities.

We also received a small donation of \$50 and ticket sales of \$570 from Dr Jac den Houting's Masterclass.

# **Marketing** & comms 10% **Establishment Autistic** costs & NDIS employees & requirements contractors 21% 45% **Other program** costs 24%

# Where were they spent?

Financial Results: Period to 30 June 2020

DPFO grant*	\$
Revenue	113,150
Management and consulting fees	(20,639)
Employment expense	(34,829)
Marketing	(11,981)
Program costs	(41,701)
Evaluation	(4,000)
NET FOR THE YEAR	and the second

ICB grant and all other activity	ty	\$		
Revenue	69,4	158		
Other income		98		
Amortisation & depreciation expense	(1	.17)		
Bank fees and charges		(2)		
Employment expense	(44,0	)88)		
Insurance expense	(1,3	311)		
Technology expense	(6,8	80)		
Other expenses	(15,4	477)		
NET SURPLUS FOR THE YEAR	1,	681		
*Prepared by Plumtree Children's Services				

# Financial Position at 30 June 2020

### ASSETS

CURRENT ASSETS	
Cash & cash equivalents	281,126
Trade & other receivables	200
Other current assets	10,183
Total current assets	291,509
NON-CURRENT ASSETS	
Property, plant and equipment	4,155
Total non-current assets	4,155
TOTAL ASSETS	295,664
LIABILITIES	
CURRENT LIABILITIES	
Trade & other payables	8,963
Provisions	2,894
Other liabilities	282,126
Total current liabilities	293,983
TOTAL LIABILITIES	293,983
	-
NET ASSETS	1,681
EQUITY	
Retained surpluses	1,681
Total equity	1,681

# 6. Our people



## Elected Board

# Our people

Kathy Isaacs - Chairperson Sharon Fraser - Treasurer Dr Melanie Heyworth - Secretary Deborah Boyd - Director Timothy Chan - Director Dr Justine Noble - Director Dr Erin Bulluss - Director

### Employees

Dr Melanie Heyworth Sharon Fraser Ginny Grant Sophie Ralston Emma Marsh Stacey Kirtley

### Brand ambassador

Yenn Purkis

### Autistic collaborators

Ally Grace Cadence Danijela Turner Emma Dalmayne Dr Jac den Houting Kahukura Kieran Rose Lee du Ploy Mandar Nelson Nathan McConnell Prue Stevenson Sandra Jones Tom Bozic



Anna Cristina Celeste Josephine Art David Gray-Hammond Dr Emma Goodall Jacquelyn Fede Katie Rose Guest Pryal Kristy Forbes Leah Taylor Michelle Swan Neurodivergent Rebel Quincy Hansen Shadia Hancock Dr Wenn Lawson Bruce Meatheringham Clare Keogh Dawn Joy-Leong Green Streak Jessica Harrison Katy Reid Kylieanne Derwent Leeann Friday My Autistic Sparkle Nathan McConnell Ruby Mountford Stevie Lang William **31** 

# Our people



Kathy Isaacs, Chairperson



Deborah Boyd, Director



Dr Melanie Heyworth, Secretary & CEO



Emma Marsh, Content Producer



Sharon Fraser, Treasurer



Timothy Chan, Director



Ginny Grant, Communications Manager



Stacey Kirtley, Administrative Assistant



Dr Justine Noble, Director



Dr Erin Bulluss, Director



Sophie Ralston, Program Manager



Yenn Purkis, Brand Ambassador



# Our partners and supporters

# National Disability Insurance Scheme

Plumtree Children's Services

**Reframing Disability** 

Celeste Josephine Art

The Autistic Realm Australia











# 7. Looking forward



# Reframing Autism's 'problem statement'

Reframing Autism has identified a specific problem that we are hoping to address through our activities. This forms our 'problem statement':



The current stigma surrounding Autism derives from the sense that Autistic people are 'broken normal' people, and is fuelled by misperceptions, misunderstandings and a pathologising ideology.

This stigma compromises Autistic holistic wellbeing and results in denying the Australian Autistic community the basic human need for belonging and connection that is their right, regardless of intersectional identities, or communication and support needs.



# Addressing the problem in 2021 & beyond

### Governance

- Board expansion
- Board training
- Intersectional Advisory
   Committee

### Accessibility and inclusion

- Captioning
- Easy English translations
- DIAP

### CPD

Offer CPD to various Allied Health, diagnostician & education professionals providing services to Autistic families

### Alternative therapies

 Develop evidenced Autistic-led therapies to substitute for EIBIs

### Resources

- E.g., position
  statements, protocol
  of practice for birth
  workers supporting
  Autistic women
- Picture book

# Social media and content

 Continue with social media presence, incl. original content (blogs, memes, podcasts) & sharing content.

### Workshops

 Continue regular live workshops (COVID-19 restrictions allowing), nationally

### Webinars

• Continue regular online webinars

### Retreats & Symposia

• At least biannually, rolling out nationally

### Research

 Continue to conduct & contribute to coproduced research in Australia and internationally Systemic advocacy and building partnerships



Reframing Autism would 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.



Artwork by Celeste Josephine Art, (c) 2019, 2020