

REFRAMING *DISABILITY*

ANNUAL REPORT
FOR 2019-2020



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ABOUT THE ORGANISATION

Reframing Disability is a company limited by guarantee, run by parents and families, for families of young children with a delay or disability. We combine capacity-building and leadership development with education, research, resource development, mentoring, and support.

Reframing Disability offers a space for families to come together to understand their role in creating a future of possibilities for themselves and their child. We promote respect, acceptance, empowerment and citizenship.

Our vision and goals align with the Australian National Disability Strategy 2010-2020, the United Nations Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child.

OUR HISTORY

Reframing Disability was auspiced by Plumtree Children's Services in June 2019, with funding from the National Disability Insurance Scheme (NDIS) under the Program Name 'Community Inclusion Capacity Development' and Activity Name of 'Information Linkages and Capacity Building (ILC) Readiness Round 2018-19'.

Plumtree is a not-for-profit organisation that provides support for young children aged birth to 8 years old with a developmental delay or disability and their families.

Plumtree incubated this initiative prior to auspicing the organisation by dedicating financial and organisational resources with the intention it would become independent in due course.

OUR VISION

To create a world that promotes respect, acceptance, empowerment and citizenship of children with delay or disability and their families.

OUR MISSION

Empower families to empower children to become leaders of their own lives.



OUR GOALS

Reframing Disability offers a way for families to see a future of possibility for their children by building their empowerment, participation, control and leadership through peer led training and coaching. Our focus is parents, families and carers who have children with a developmental delay or disability and other vulnerable children.

Working with the evidence from positive psychology and family leadership we will support families to set a positive vision for their family, child and self along with practical support to stay focused on achieving these goals.

We will also share our expertise with other professionals and organisations through the promotion and development of new family-centred and strengths-based practices and authentic partnerships.

OUR OBJECTIVES

1. To empower parents through leadership and peer networks to meet the needs of young children with developmental delays or disabilities and their families by embracing the principles of acceptance, respect, and neurodiversity.
2. To provide an accessible, relevant and informative website for Reframing Disability.
3. To enhance the capability of parents through training, workshops, and mentoring using positive psychology and a citizenship focus.
4. To raise awareness at a national level of the nature, role and importance of Early Childhood, and to provide representation on appropriate policy making and funding bodies.
5. To build the capacity of service providers through the promotion and development of family-centred and strengths-based practice and authentic partnership.
6. To ensure the ongoing financial sustainability of Reframing Disability.
7. To undertake evaluation and research, to ensure Reframing Disability continues to be evidence based with quality outcomes and transferability.



GUIDING PRINCIPLES

Family leadership

When each member of the family has positive relationships, is connected to their community, has an opportunity to use their strengths, is resilient and has agency (control) over the kind of life they want to live.

Strengths based

An approach that shifts the focus away from deficits to a place where an individual is seen through the lens of what they can do and what strengths and interests they possess.

Peer-led

An organisational structure in which the leadership team and key stakeholders are also parents (or care-givers) of a child with a delay or disability.

Positive psychology

The scientific study of human thoughts, feelings and behaviours with a focus on identifying and building on individuals' strengths and wellbeing.

Citizenship

That each person in society is respected, is of equal value and their differences are recognised as different, not less.

Rights-based

This UN Convention on the Rights of Persons with Disabilities (UNCRPD) protect the rights and dignity of people. Article 7 of the UNCRPD states that governments agree to take every possible action so that children with disabilities can enjoy all human rights and freedoms equally with other children. They also agree to make sure that children with disabilities can express their views freely on all things that affect them. What is best for each child should always be considered first.

Family-centred

A practice is built on the premise that parents know their children best and that they want the best for their children. A family centred approach equates to an equal partnership between professionals and family members with family members making decisions, building their capacity and feeling respected.



GOVERNANCE

Reframing Disability is an Australian Public Company, Limited by Guarantee.

Reframing Disability is registered with the Australian Charities and Not-for-profits Commission (ACNC) and has DGR status.

Structure and management

Reframing Disability is auspiced by Plumtree Children's Services until 30 June 2020, after which it will become an independent organisation. Plumtree also auspiced the establishment of another organisation, Reframing Autism.

During the auspice period, Plumtree is responsible for project management oversight and ensuring good governance of both organisations.

Margie O'Tarpey was contracted as strategic advisor and project sponsor. Ms O'Tarpey developed the initial concept and funding proposal to the NDIA under the ILC program; this was successful and set the foundation for the establishment of Reframing Disability. Her initial role was to oversee the governance and establishment of Reframing Disability as an independent organisation, delivery of the project plan, and to support the strategic direction of the interim committee.

Joint steering group

A joint steering group was formed and includes the CEO of Plumtree, Project Sponsor, Executive Officer of Reframing Disability and CEO of Reframing Autism.

The purpose of the joint steering group was to ensure effective communication, management and coordination of the ILC projects. The joint steering group will cease to meet once the auspice period ends at the end of June 2020.

Role of the board

The board of directors is responsible for oversight and governance of Reframing Disability. It is the board's responsibility to identify the organisation's strategic direction and goals.

The board supervises the organisation's overall business performance, ensuring the organisation develops and implements strategies and supporting policies to enable it to fulfil the objectives set out in the organisation's constitution. The board delegates the day to day management of the organisation but monitors and supports management in an ongoing way. The new board will be appointed at the AGM in May 2020.



REPORT FROM THE CHAIR AND EXECUTIVE OFFICER

We are proud to present this report as we mark the momentous milestone of our first year.

In June 2019, Plumtree Children's Services auspiced the establishment of Reframing Disability as an independent organisation, with funding from the National Disability Insurance Scheme (NDIS). We want to thank the NDIA for their support and commitment to improving the lives of people with disabilities and their families.

Reframing Disability evolved from the work that Plumtree has been doing for many years in building family leadership and employing parents as peer workers. We want to thank Sylvana Mahmic, the Plumtree Board and team for your support and having the commitment to families and the vision to take Reframing Disability to the next level.

We are grateful to Margie O'Tarpey, our project sponsor, who has expertly organised the setup and governance for the new organisation and provided strategic advice and direction over the past 12 months.

Reframing Disability aims to increase the capacity of parents of young children with a disability because, in these early years, it is the parent who makes the biggest difference.

We are dedicated to our mission of empowering families to empower their children to become leaders of their own lives and changing those first messages that families hear so that they can start from a point of hope and possibility.

This period has been a time of establishment and direction setting, pursuing partnerships and identifying opportunities. Since launching, we have co-hosted a family conference attended by over 200 families, held online webinars, programs and peer groups, started a mentoring program for families, launched our website with stories and resources from families and are building a social media presence. We have created partnerships with incredible organisations that have a shared vision of the best life for people with disabilities and their families.

It is early days for Reframing Disability, and the next twelve months will see the organisation grow and develop. As we move forward and look to the future, we plan to expand our programs and resources and grow our partnerships, so that families can create a better life for their child by building their empowerment, participation, control and leadership.

We are grateful to many who have supported Reframing Disability in its first year. Thank you to our skilled and knowledgeable board of directors for your commitment and hard work, the team of peer workers and parent contributors for your incredible efforts, and to all of the families who have connected with us, and our partners and allies.

We are thrilled to be working together as Chairperson and Executive Officer in this exciting family-led organisation, and to continue working with the board, team, partners and families.



KATE MCNAMARA
Chair



STACEY TOUMA
Executive Officer

BOARD OF DIRECTORS

Reframing Disability is guided by a dedicated board with diverse skills, united by their commitment to children and families. Our board members have lived experience of disability.



Kate McNamara, Chair

Kate has always worked in policy and planning in the community services sector. Since the birth of her daughter Bridget in 1997, Kate has turned her attention to all things disability. Because of Kate's commitment to inclusion, planning and driving an agenda, Reframing Disability was an obvious area of interest. In 2006 Kate established the MyTime program for Tresillian. Since then she has developed and coordinated these MyTime groups throughout NSW.



Joshua Williamson, Treasurer

Joshua Williamson has been a professional economist for over two decades. He is currently the Head of Economics for Australia and New Zealand for Citi, a diverse global financial services company. His interest in the disability services sector started from his own experience as a parent of children with additional needs. Joshua's interest in Reframing Disability comes from wanting to help change perceptions of disability and to improve the inclusion of those with disabilities and their families in the community.



Glenn Redmayne, Director

Glenn is the Access and Inclusion Planning Leader at Inner West Council and has over 24 years' experience in local government. As an advocate Glenn is a former executive member of the Disability Council of NSW, board member of PDCN and PWD NSW. Glenn is keen to draw on his lived experience to help families and children on their journey to be resilient informed participants of their own lives and choices. He is passionate about making inclusion a reality and for RD to be a platform to help the next generation.



Justine Flynn, Director

Justine was part of the team that developed Blue Water High, she created Islandares and co-created Bindi's Bootcamp and has directed for Nickelodeon, Dirtgirlworld and The Justine Clarke Show. Justine is the creator, showrunner and director of the ABC/Netflix series The Unlisted and a children's author having published Miss Mae's Saturday and The Unlisted trilogy. Justine is an advocate for parent training, attachment and trauma support, particularly focusing in the area of foster care and adoption. She runs an online support network for adoptive parents and is mother of five beautiful children, her third has Autism.



Sylvana Mahmic, Director

Sylvana is the CEO of Plumtree and an advocate for early childhood intervention and self-management. She has served on over 15 reference and advisory groups in addition to five Ministerial appointments. Sylvana has worked for over twenty years in the early childhood intervention field, with a particular expertise in a whole of family and community approach to early childhood intervention. She has a son who has cerebral palsy and an intellectual disability. He has been utilising self-managed funding since 2009.



Clayton Buffoni, Director

Clayton has a rather diverse past. Former Stage Writer and Director in the UK, Journalist in the West Bank, Gaza and East Jerusalem and National Business Development Manager for Langton's Fine Wines in Australia and NZ for the last 15 years. Currently, Business Development Consultant to Plumtree Learning. One part of a neurodivergent family of three and Now and Next Alumni member.

OUR PEOPLE

Peer workers

Reframing Disability employs parents and carers of children with a delay or disability as Peer Workers. Our Peer Workers are trained and employed to support other families facing similar challenges. Peer Workers have a broad set of skills from their professional background & personal experience that they draw upon when supporting families.

The shared life experience of Peer Workers and families enables a level of empathy and trust that helps improve the outlook and attitude of parents & further provides an alternative to a purely clinical approach to supporting the needs of children with disabilities and their families.



Margie O'Tarpey, Project Sponsor

Margie O'Tarpey is an accomplished CEO, with over 30 year's experience in the Not for Profit sectors, primarily in health and community services and professional Associations. Margie has a background in law, social work & nursing. She is recognised for her ability to lead people through change; being an innovative thinker, with a strategic focus. Margie is committed to supporting Reframing Disability with building a strong foundation, good governance and financial sustainability.



Stacey Touma, Executive Officer

Stacey manages the daily operations and activities of Reframing Disability and works closely with the Chair of the board. Stacey is Hub Leader of the Peer Workforce at Plumtree and has managed a number of projects for Plumtree. Stacey is a mum of 3 and her middle son Alex has Williams Syndrome. She draws upon her lived experience and knowledge of evidence-based strategies, to support and empower other families with the skills and resources to help their child and family.



Mogi Bayasgalan, Peer Worker

Mogi oversees the evaluation of Reframing Disability's programs and activities, as well as coordination and development of workshops. Mogi's professional's expertise is in Tax Economics and she loves telling stories through the medium of numbers, spreadsheets and graphs. Mogi believes, as a mother of an autistic son, in the importance of following the child's interests and strengths, creating opportunities to foster their talents and most importantly listening to the children and believing in them from the early childhood.



Kylie Aekins, Peer Worker

Kylie is a peer mentor and facilitator of MyTime. She supports families with evidence-based, child-led, strengths-focused, mindfulness & growth mindset approaches. She is an experienced Naturopath, Doula and Peer Facilitator of empowering parent and disability programs. Kylie is a mum to two amazing neurodiverse school-aged kids. Her family lives the day to day journey of what a medical & disability diagnosis means. Her youngest is also Autistic & has taught her new perspectives she didn't realise she needed.

Contributors

We are so grateful to our community of parents, carers and supporters who contribute in many different ways. Their contributions include design, communications, social media, sharing their stories, mentoring other families, and so much more!

HOW WE SUPPORT FAMILIES

Reframing Disability aims to build the capability of parents of young children with a disability, because in these early years it is the parent who makes the biggest difference.

We deliver clear consistent messages of hope, possibility, belonging, a life of purpose and self-management to families from the start of their journey which continues to build over the years. We create a mindset shift by highlighting the critical role played by family, community and peers. In doing so, we empower families to empower their children to become leaders of their own lives.

Our programs and resources are co-designed with families and are based on evidence and needs. Building on our existing activities they focus on positive outcomes rather than increased amounts of therapy. We provide contemporary approaches relevant to families of young children.

Learning and development

We host online workshops and webinars that offer an opportunity for parents to learn from family leaders and professionals.

Our educational programs cover topics that increase family's capacity in understanding what their child's disability means for the future, navigating early childhood intervention and best practice, NDIS, creating connections in the community and other topics identified by families.

Mentoring

Our mentoring program provides information and capacity building to families through an online, one on one flexible and adaptive mentoring approach to suit the needs of individual parents.

It aims to improve child and family outcomes, family functioning and quality of life for the child with a disability and family. The mentoring program builds parents confidence and skills through increasing their agency and empowerment.



HOW WE SUPPORT FAMILIES

Information and resources

We have developed information and resources to assist families to navigate the day-to-day realities of their child's disability and family life. These resources include blog posts highlighting parent stories, tip sheets and content for social media.

We will continue to develop a series of information and resources to assist families make informed choices for their children, and to educate professionals and the wider community. Resources will be a combination of 'by and for families' resources highlighting parent stories & strategies, and by professionals to build parents skills.

MyTime

We offer what every family needs, a community. A place where they are not alone. We have partnered with MyTime to deliver two MyTime peer groups online.

The groups are for parents and carers of children with a disability, developmental delay or a chronic medical condition. It's a space for parents and carers to come together to share information and build a network. A safe space to get help with everyday life, as well as looking at the big picture.

Our groups are run by parent facilitators who understand what it's like to have a child with a disability and have extensive knowledge of the early childhood intervention sector and NDIS. The online format means that parents can connect from the comfort of their own home.

Family Conference

In 2019 we hosted our first Conference in partnership with Plumtree, Now and Next and Reframing Autism. The conference brought together 200 families of children with disabilities, people with disabilities and their allies.

The conference delivered an engaging program celebrating and highlighting the benefits of an approach in which disabled people and families lead their communities.

We will continue to partner with Plumtree to co-host this event in the future.



OUR IMPACT

334

Families attended workshops & events

2,108

Website views since November '19

12

Blog posts written by parents sharing their story and experiences

16

Parent contributors who volunteer their skills and support

Facebook

478 Likes
519 Followers
13,208 Post Reach

Conference

22% dads attended
Conference met expectations:
72% Strongly agree
28% Agree

10

OUT OF TEN

Families rated our individual Peer-to-peer mentoring sessions 10/10 in terms of Relationship with mentor, Goals and topics discussed during the session, Mentor's approach and Method used, and the overall satisfaction of the mentoring sessions.



FEEDBACK FROM FAMILIES

Parents reflection after two peer mentoring sessions

Before we started with our mentor, our family was feeling stuck, overwhelmed, stressed, isolated, lacking direction and not knowing what were the next steps we should take. We were waiting on finding an available Speech Therapist to support our sons communication goals. Our son is starting school next year but we were unsure what formal supports he needed most to assist him with the transition to school. As a family we had no clear goals that we were working towards even though we have an NDIS plan and support worker for two hours each week. We were inconsistent with what we were doing and slightly confused as to what was a priority to our family. After two mentoring sessions, we feel like we have come together as a family with a clear vision of what we want and need. We now have a plan on how to support our child and what goals are important. We now understand our child's NDIS goals which were not very clear of prior to mentoring. We now know what we want to focus on to get him ready for school.

~Parents of 4 year old Autistic son and 20 month old son

Family Conference

The conference was amazing. I love the diversity of the speakers who bring personal stories, deep passion and knowledge to their presentations.

~Parent

I loved hearing from people with a disability and their families. It helped me think about my own bias i bring into my work as a clinician. I loved hearing the personal stories.

~Allied health practitioner

The conference was so good and we are thankful for being able to attend. All the information presented and guidance given to help our daughter feel heard, understood and included in all aspects of her life has been great. Great hearing about other parents journey's, experiences and challenges. It's been invaluable learning.

~Parent



ACHIEVEMENTS

Setup of the organisation

Reframing Disability was setup as an Australian Public Company, Limited by Guarantee. The organisation was registered with the Australian Charities and Not-for-profits Commission (ACNC) and has DGR status.

A constitution was drafted and approved, outlining how the organisation will be structured and governed and its main activities. It also explains the roles, responsibilities and powers of the board, directors, and management.

A board of directors were appointed, and the first meeting was held in August 2019.

Partnerships

We partnered with:

- Physical Disability Council of NSW (PDCN) to receive financial support to deliver peer mentoring to families of young children.

PDCN is the peak representative organisation of, and for, people with physical disability across New South Wales.

- MyTime to launch two online peer support groups for parents and carers of children with a disability.

MyTime funding is provided by the Australian Government Department of Social Services, and the program is coordinated nationally by the Parenting Research Centre.

Website

Our website was launched on 21 October 2019. In addition to information about the organisation, the website hosts the interactive calendar for our learning and development program and resources including parent stories and tips.

Stakeholder launch

Reframing Disability launched to over 50 stakeholders representing the disability, early childhood intervention, government and corporate sectors.

The launch was an opportunity for key stakeholders and influencers to come together to network, celebrate and mark the momentous occasion.

Family conference

We partnered with Plumtree, Now and Next and Reframing Autism to co-host a Family Conference. It was held in Sydney's Inner West and attended by over 200 families, people with disabilities and allies.

Reframing Disability hosted a break out stream with three sessions. These sessions were presented by parents and highlighted the role of families in the early years, creating community connecting and building independence through self-management and tips.



ACKNOWLEDGEMENTS

Reframing Disability is grateful for the support of the families who have engaged with the organisation.

We also recognise the significant support from a range of organisations and people throughout the year, including:

- National Disability Insurance Agency
- Plumtree Children's Services
- Margie O'Tarpey, Project Sponsor
- Board of directors
- Reframing Disability team
- Parent contributors
- Reframing Autism
- Physical Disability Council of NSW
- MyTime

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