

Rainbow Families

National Autism Strategy

*We consent to this submission to be published*

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## About Rainbow Families

Rainbow Families was formed in 2015 as the peak body for lesbian, gay, bisexual, transgender, intersex, and queer (LGBTQ+) families. The mission of Rainbow Families is to build a community that fosters resiliency by connecting, supporting and empowering LGBTQ+ families.

Rainbow Families has a growing membership and includes people from across Australia. Rainbow Families is an incorporated organisation, governed by a constitution which provides a structure for how the group operates. Rainbow Families is a registered charity and has DGR status from the ATO.

## What is a Rainbow Family?

A Rainbow Family is a LGBTQ+ parented family. At Rainbow Families, we define a Rainbow Family as: any lesbian, gay, bisexual, transgender, queer or intersex person who has a child or children; or is planning on having a child or children by way of donor insemination (known or unknown), surrogacy (altruistic or commercial), foster care, foster to adoption, adoption (domestic or international), opposite sex relationship, coparenting or other means.

Rainbow families, like many modern families, come in all shapes and sizes and are formed in many different ways. The thing we all have in common however, is that our families are created through love. Over thirty years of peer reviewed research into same-sex parented families shows that children from these families do as well as their peers from heterosexual-parented families.

## What we do

We provide support and resources to members of the LGBTQ+ community so that they and their families can live their best and most colourful lives. We host events that connect LGBTQ+ families, particularly those that are feeling isolated because of social pressures, financial difficulty or where they live. We advocate on behalf of our community and are a strong and consistent voice for LGBTQ+ families to address discrimination, raise awareness and promote acceptance. We collaborate with similar organisations from other states to push for change across the nation.

## **Submission on the National Autism Strategy**

Thank you for the opportunity to contribute to the development of the National Autism Strategy. We are pleased that priority is being given to addressing the whole of life needs of Autistic people and acknowledging the diversity of the Autistic Community, with specific reference to LGBTQ+ people.

## **Background**

In 2021, Rainbow Families NSW established the Neurodiverse Families social group for LGBTQ+ parents and carers who are neurodivergent and/or have children who are neurodivergent. There is also diversity of gender and sexuality among young people in these families. The main point of contact for the group is a private Facebook page which now has 173 members.

The group members are diverse in their geographical spread and life circumstances. They are from across the country and are partnered, solo, separated and co-parenting. They are Autistic and have co-occurring conditions including ADHD, dyslexia, dysgraphia. Some are formally diagnosed and some are self-identified.

The group has provided a safe space for LGBTQ+ parents to share experiences and ask questions which are primarily, but not exclusively parenting-related. Members share resources, information and events and use the Facebook page as a means of connecting with each other and arranging social events.

Discussions encompass various challenges of being neurodivergent in a neurotypical world including masking, burnout and sensory needs. Experiences and advice are shared on a breadth of issues such as access to assessment and support services and neuro-affirming health care and education.

We asked our community how a National Autism Strategy could support them as Autistic individuals and parents of Autistic children.

## **Social inclusion**

The key to promoting social inclusion for Autistic individuals and families is increasing awareness and understanding of autism in the general community. This enables more open discussion which provides opportunities for Autistic people to share their experiences and deepen understanding.

Our community is acutely aware of issues of representation of marginalised groups and the importance of accurately conveying authentic and diverse experiences and not reinforcing stereotypes and misconceptions. Portrayal of Autistic people in the media and popular culture still falls far short of representing the diversity of the Autistic population.

People who are assigned female at birth (AFAB) and others whose presentation does not fit prevailing stereotypes of autism are often disbelieved and dismissed. They expend a

good deal of mental and emotional labour educating others and attempting to rectify misinformation.

According to one community member:

*“More and more people are discovering they are Autistic later in life because we were missed because even the professionals didn't see beyond the stereotype - and now we are identified as Autistic, everyone is questioning us and doesn't believe us.”*

Knowledge of key concepts such as masking; uneven skill profiles; dynamic functionality and cycles of burnout can go a long way to understanding the reality of Autistic people's experience. For too long, views about Autistic people and their needs have been based on neurotypical perceptions of external behaviour while the internal experience of the Autistic person is disregarded. It is also important that people understand the impact of neurotypical environments on Autistic people and the collective responsibility to ensure that the spaces that are part of our lives are accessible and inclusive to all.

Given the significant overlap between LGBTQ+ and neurodiverse populations, it is surprising how few spaces there are for Autistic people to connect with others in ways that accommodate their needs. It is hard enough finding a safe space as an LGBTQ+ person without having the additional layer of need that comes with being neurodivergent.

As it is, the number of dedicated LGBTQ+ venues has been decimated in the last two decades and outside of inner city areas there is no assurance that mainstream venues will be welcoming. Opportunities for LGBTQ+ people to gather socially are largely limited to organised events in pubs and clubs or through major events such as Mardi Gras. For families with neurodivergent children, opportunities are even more limited.

A notable feature of the LGBTQ+ community is that events tend to occur in high sensory environments. The need for low-sensory and low-cognitive demand environments has been recognised by the organisers of events like Mardi Gras and in mainstream attractions such as museums.

However, community volunteer-led organisations like Rainbow Families have limited options for facilitating social events for our Autistic members. Usually outdoor venues like parks are the only option and these are subject to safety requirements such as fencing from traffic as well as the changeability of the weather.

While being able to connect regularly with other LGBTQ+ families is important, so is feeling included in the broader Autistic community. LGBTQ+ Autistic people and their families attending Autistic events need to be confident that diverse families are accommodated and welcomed.

There is scope for innovative approaches to Autistic social events, including interest-based groups that don't depend on high-sensory demand venues. However, someone needs to

facilitate them and depending on unpaid voluntary efforts of Autistic individuals with already demanding lives is unsustainable and unfair.

Ideally, Autistic-led organisations, including those within the LGBTQ+ community would be supported to develop initiatives through grant programs and public sector venues being made available for events. Further, mainstream LGBTQ+ organisations should be encouraged to explore ways of making their events more accessible and inclusive for Autistic people in their communities.

## **Participation in education and employment**

Members of our community already experience challenges interacting with their children's day care centres and schools if there isn't sufficient understanding of family diversity. Navigating educational settings designed for neurotypical children adds another layer of demand on families.

*One parent told us: "The biggest thing for us in our experience has been the education system and lack of understanding. The experience of Autistic kids is severely misunderstood."*

Frustration with the mainstream school systems often comes up in discussions in the group. Inadequate responses to accommodating a child's sensory needs and persistence of disciplinary regimes based on behaviourist approaches are common experiences. The transition from primary school to high school is particularly challenging, especially for children with co-occurring conditions such as ADHD. Some parents elect to homeschool their children after exhausting the options in the school system and dealing with the impact on their children's mental and physical health.

In the workplace, we experience the same challenges as the general Autistic population and may feel as though we are having to 'come out' a second time. However, being Autistic often has a more immediate and profound impact on their experience in the workplace.

One community member expressed their *"Lack of confidence in their employer and colleagues to treat me equally and to be a safe workplace."*

*Another said: "As an Autistic employee, securing workplace accommodations can feel like an uphill battle because the burden is on me to keep justifying my needs rather than the employer being proactive about providing an accessible workplace."*

Most workplaces are based on systems and processes designed for neurotypical employees with the assumption that it is the normal way of doing things. Autistic parents with substantial demands in their personal live experience additional challenges in obtaining and sustaining paid employment and require empathy and a flexible approach.

There are already Autistic-led organisations and individuals providing workplaces with education about Autistic lived experience and the needs of Autistic people in the workplace. Some work with employers to help ensure that their processes are accessible and culture is inclusive for Autistic people. The National Autism strategy provides an opportunity to harness the expertise and passion of people working in this space to scale up their efforts across a range of workplaces settings.

## **Access to neuro-affirming and inclusive diagnostic services and supports**

Our community experiences the same issues as the general community in accessing autism assessment processes. Waiting lists are long and it is not unusual to wait for more than six months to see a practitioner. Booking an appointment can in itself be a drawn-out process due to many practitioners closing their books to new patients. Issues are even more acute in regional and remote areas. While there is some Medicare coverage for autism assessments for children up to 13, there are still significant out of pocket costs.

There can be additional challenges on top of those already faced by LGBTQ+ families as a parent in our community explains:

*“As a gay dad I have been advocating on behalf of my family since before my child was born. Advocating for our family to be tolerated, accepted and sometimes even celebrated. This self advocacy is exhausting. With my daughter’s recent autism diagnosis, I am daunted at the thought of now having to advocate for our family on a whole new front.”*

Adults wanting to be assessed face cost and geographical barriers to accessing mental health practitioners who are appropriately qualified and there is no Medicare relief. People who are assigned female at birth and others with non-stereotypical presentations of autism commonly encounter practitioners who are not familiar with the diverse presentation of autism. Some have experienced mental health challenges throughout life but their autism has been missed or misdiagnosed.

While self-identification is considered valid within the autistic community, it is required for external purposes, most notably NDIS applications. It is a significant concern if vulnerable people in need of support are unable to access it due to cost and other barriers to diagnosis.

For children and adults, the diagnosis process needs to be better integrated with the process for obtaining support. Parents of newly-diagnosed children face a labyrinth of information but little guidance. Unfortunately a lot of the information they receive even from well-meaning professionals is not-neuroaffirming but deficit based and ableist.

As one parent told us: *“There needs to be recognition that there is nothing wrong or bad with being Autistic. It’s actually that the systems we have created and society we live in is so ableist and still heavily reliant on medical models and behaviorist approaches.”*

There needs to be a move from forcing Autistic children into a punishing raft of ‘therapies’ scrutinising their efficacy and benefit to the child. Parents feel pressure to force their children into a range of interventions as a matter of urgency before their child becomes too Autistic. They are encouraged to believe that Autistic tendencies can and should be nipped in the bud and replaced with acceptable neurotypical behaviour. Autistic adults who experienced these kinds of coercive treatments as children are testament to the long-term damage caused to mental health including Complex PTSD. Their concerns need to be taken seriously, not dismissed because they are inconvenient for some people to hear.

Parents are given information about ‘social skills’ courses that aim to shape children’s behaviour to fit in with their neurotypical peers. What Autistic children really need is peer-based support in supportive environments where they can be themselves and develop social skills organically. However, it can be difficult to find as one parent said: *“I’ve found a huge gap in finding peer support for my teen. And I believe the gap gets larger the older you get.”*

There also tends to be a false-binary drawn between parents of Autistic children and Autistic adults despite the strong genetic component of autism. Many Autistic parents remain unidentified because they have placed all their energy into getting their children assessed and managing their care. Practitioners need to take a more holistic approach to families and make appropriate referrals for parents if Autistic children are to be properly supported.

Autistic parents tend to be more familiar with neuro-affirming sources of information from within the Autistic community and can often point non-autistic parents in the right direction. It’s crucial that parents of newly-diagnosed Autistic children have information from Autistic people who can provide insight into the internal experience of autism. Too much information is centred on the experiences of Autistic people based on neurotypical observations of external behaviour and the impact on other people.

Newly-diagnosed Autistic adults also experience difficulty finding support that is appropriate to their needs. Most services in this space are targeted to parents of Autistic children or young adults transitioning from school. It is not suggested that this is less of a need but that support services must address needs of Autistic people across all life stages. The needs of adults diagnosed later in life are also different from those who have grown up knowing they are Autistic and need support in making the adjustment from a neurotypical life.

Support also should be available without having to get over the hurdles of obtaining a diagnosis and qualifying for the NDIS. Rather than a zero-sum game determining who does and doesn’t get support, there needs to be a more nuanced approach that respects the



individual's assessment of their needs. The starting point needs to be openness to diversity of experience and willingness to listen and understand.

## **Health and Mental Health**

According to findings arising from the 2021 Census, the LGBTQ+ population experiences poorer mental health when compared with the general population.

People who are neurodivergent and LGBTQ+ experience complex mental health profiles due to social exclusion and isolation compounded by lack of acceptance of gender diversity and sexuality by their families and broader community.

It is crucial that all healthcare providers understand the challenges for Autistic people accessing health services in term of ableist systems and processes and inadequate communication. Processes can be confounding and frustrating and it can feel as though there are endless obstacles to overcome. Things like making appointments and arranging referrals can be onerous and usually not straightforward as service providers assume.

Health care providers need to recognise the particular challenges faced by late diagnosed adults at different life stages, including the cumulative effect of masking, burnout, trauma and general life stressors. In addition, the interaction of co-occurring conditions and for assigned female at birth individuals, menstruation and menopause. For LGBTQ+ individuals, it is important that treatment of these issues is not driven by heteronormative assumptions.



## Recommendations

We recommend that the following be explored as part of the National Autism Strategy.

### Social inclusion

- Funding for Autistic-led organisations to provide opportunities for social connection in neuro-inclusive environments, including initiatives that are LGBTQ+ focused.
- Funding for mainstream LGBTQ+ organisations to explore ways of making events more inclusive for Autistic members of their communities in consultation with Autistic-led organisations.

### Participation in education and employment

- Changes to make school systems and processes more inclusive of the needs of Autistic students including moving away from behaviourist disciplinary approaches.
- Scaling up of workplace education about Autistic lived experienced provided by Autistic-led organisations.
- Encouraging employers, particularly large corporations and public sector agencies to work with Autistic-led organisations to develop processes that support Autistic employees, including workplace adjustments, mentoring, peer support and advocacy.
- Strengthening the legislative framework to place a positive obligation on employers to provide an accessible workplace environment for all employees.
- Meaningful career planning available in school and beyond.

### Access to neuro-affirming and inclusive diagnostic services and supports

- Diagnostic guidelines and education to ensure that practitioners are familiar with the diversity of Autistic presentations.
- Ensuring that parents receive neuro-affirming information driven by a social model approach to Autism rather than medical model approaches that pathologise and limit autonomy.
- Greater scrutiny of harmful behaviourist 'therapies' particularly when funded under the NDIS
- Post-diagnosis pathways that are integrated with the process of obtaining support and tailored to the needs of Autistic individuals.
- Better integration of services at different levels of government and with the private sector to address gaps in service provision.
- Funding Autistic-led organisations through ongoing grant programs to provide telephone information and referral, peer support, mentoring, courses, and other means of supporting newly identified Autistic adults.

- Development of a government-backed website providing a gateway to reliable and neuro-affirming information and resources for parents of Autistic children and Autistic adults.
- More support to be available outside the NDIS and for Autistic people who have not received formal diagnosis.

## **Health and mental health**

- Provision of clear, sufficiently detailed information about healthcare in a variety of formats.
- Clear signage and making information and maps available online ahead of appointments.
- More attention to the sensory and cognitive impact of healthcare environments.
- Better co-ordination of health services to take the burden of mental labour off the individual.
- All staff who have contact with the public to be educated about the needs of Autistic people.
- Better co-ordination between health providers to relieve Autistic people of some of the organisational burden.
- Training to ensure mental health practitioners are neuro-affirming care and understanding of intersectional dimensions.