

Response to the Draft National Autism Strategy May 2024

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Introduction

Mallee Family Care (MFC) welcomes the opportunity to provide feedback on the government's Draft National Autism Strategy, and commends the vision of a safe, inclusive society where autistic people can fully participate in all aspects of life.

MFC provides a unique perspective as a place based, not-for-profit community service organisation (CSO) that has been supporting the regional, rural and remote communities of northwest Victoria and far west New South Wales since 1979.

Our organisation employs almost 300 staff to deliver more than 70 federally and state funded programs reaching thousands of community members across the Mallee region. These programs span family, youth and children, disability, mental health, housing, legal, financial, research, education, philanthropy, and advocacy.



MFC embodies what it means to be truly place-based, creating and leading local solutions targeted to the specific needs of our community. We are committed to ensuring that clients get the right support, in the right environment, at the right time. We work tirelessly to achieve the best outcomes for vulnerable children, individuals, and families, who are facing disadvantage.

In our response below, we suggest enhancing the vision of the strategy with a place-based approach to ensure comprehensive support and integration of services within local communities. This approach promotes the inclusion and empowerment of people with autism in community decision-making processes. We also offer enhancements to strengthen the strategy's vision, goals and commitments.

As advocates for rural and remote communities, we recognise the importance of providing affordable, timely and suitable services closer to home. In rural and remote areas like the Mallee, there also needs to be more timely access to appropriate assessment, diagnosis and therapy. Addressing workforce shortages and ensuring continuity of care are crucial for achieving this.

Importantly, we also emphasise centering the voices and experiences of people with autism in developing and implementing the strategy, and call for a commitment to co-delivering the strategy with the autistic community, ensuring active involvement and leadership.

Response to the Draft National Autism Strategy

The draft Vision for the National Autism Strategy is "... for a safe, inclusive society where all Autistic people are empowered to fully participate in all aspects of life, in line with international human rights."

Q. Do you have any ways to improve the Vision? If yes, please list them.

Mallee Family Care (MFC) supports the vision for the Draft National Autism Strategy of a safe and inclusive society where all autistic people are empowered to fully participate in all aspects of life, in line with international human rights. This vision reflects the core principles of acceptance and inclusivity that guide our work in the Mallee region. Our organisation believes that every person with autism has unique strengths, abilities and attributes that should be recognised and valued by society. We work to foster community understanding and acceptance of people with autism and other neurodivergence in order to create a more inclusive and supportive environment for all.

MFC suggests embedding a place-based approach into the vision as we feel this is the best way to deliver a genuinely integrated and comprehensive strategy which supports the integration of services, such as health, education, and social care, within the community, providing comprehensive support for individuals with autism and their families. We believe that a place-based approach would also encourage the inclusion and empowerment of individuals with autism and their families in decision-making processes in all aspects of community life.

MFC also stresses the importance of a joint Commonwealth-State commitment to the Vision to ensure the successful implementation of the strategy.

The draft goal for the National Autism Strategy is "... to improve life outcomes for all autistic people"

Q. Do you have any ways to improve the goal? If yes, please list them.

MFC supports the goal of the National Autism Strategy to uphold the rights of all people with autism to be respected and safe from discrimination, violence and abuse. We support efforts to ensure that autistic individuals are protected from all forms of harm and that their rights are upheld in all aspects of their lives.

As a regional provider of comprehensive services to individuals and families, we stress the importance of a place-based approach to improving life outcomes for people with autism. This needs to include the involvement of local stakeholders, such as schools, healthcare providers and community organisations, to provide coordinated support across services and stages of life. By providing services locally, people with autism and their families can build stronger social connections and support networks within their community. Place-based services can also be more culturally relevant, respecting and incorporating local customs, languages, and practices, which can improve life outcomes, in particular for people from marginalised communities. Utilising the knowledge and expertise of local professionals who understand the specific context and needs of the community can also enhance the effectiveness of services.

MFC also highlights the importance of working with stakeholders to develop a detailed roadmap, with measurable KPIs, to achieve this goal. This should include a commitment from state/territory governments to work collaboratively with the Commonwealth to ensure a coordinated approach.

Q. Do you have any ways to improve the Guiding Principles? If yes, please list them. For example, you may like to tell us if you think the wording is clear or if there are any principles missing.

MFC supports the Guiding Principles outlined in the Draft National Autism Strategy. As an organisation dedicated to promoting the wellbeing and inclusion of all in the community, we believe that the principles of partnership, accessibility, self-determination, and inclusivity are crucial in shaping a more equitable and supportive society for people with autism.

In alignment with the United Nation Convention on the Rights of People with Disabilities, MFC supports a biopsychosocial model of disability and a strengths-based and neurodiversity-affirming approach to the developed of policies, strategies and programs impacting people with autism.

We believe that accessibility based on universal design is essential to ensure that the Strategy is inclusive and accessible to all individuals, regardless of their abilities or circumstances. We support the co-leadership of autistic people is crucial in driving the development and implementation of the Strategy to ensure that it reflects their priorities, values and lived experiences.

MFC particularly welcomes the focus of the strategy on self-determination and autonomy for people with autism. By empowering autistic individuals to make their own decisions about all aspects of their lives, we believe that the strategy will help promote their freedom of choice, control, and support and enhancing their quality of life.

Q. Do you have any other feedback about the Commitments for Social Inclusion?

MFC supports the findings and recommendations outlined in the strategy on social inclusion. These reflect MFC's mission to promote connected and inclusive communities by embedding diversity and equity practices at the centre of everything we do.

MFC believes that social inclusion is not just a concept; it is a fundamental human right that ensures every individual has the opportunity to learn, work, connect, and collaborate with others, irrespective of their neurodiversity. We welcome the strong focus of the strategy on social inclusion and believe that when everyone is included, our communities thrive.

MFC understands that social inclusion is particularly important for people with autism who frequently experience discrimination, isolation and limited opportunities for participation in community life. These challenges are further exacerbated by factors such as poor employment rates, inaccessible environments, and a lack of understanding about autism within society.

To address these barriers and foster greater social inclusion for autistic people, we endorse the following commitments outlined in the report:

- Improving understanding and attitudes: Public education and awareness campaigns, increased representation in media and the arts, and the creation of accessible spaces are crucial steps towards challenging stigma and promoting acceptance of autism within society.
- Enhancing social connections: Creating opportunities for peer support and community engagement is essential for combating isolation and fostering a sense of belonging among Autistic individuals.
- Improving service delivery: Ensuring that government services are accessible and responsive to the needs of Autistic individuals is paramount for promoting their wellbeing and autonomy.
- Advocating for legal protections: We support efforts to ensure that the rights of Autistic individuals are safeguarded through amendments to relevant legislation, such as the Disability Discrimination Act.

Q. Do you have any other feedback about the Commitments for Economic Inclusion?

MFC recognises the importance of economic inclusion in improving outcomes for people with autism. Employment and financial security are vital to both improve individual wellbeing and also contribute to the overall prosperity of society. MFC welcomes the strategy's focus on the



need to increase employment opportunities, support inclusive workplace environments and provide adequate income support for people with autism.

Q. Do you have any other feedback about the Commitments for Diagnosis, Supports and Services?

MFC supports the recommendations outlined in the report on diagnosis, supports and services for people with autism. We recognise the importance of early identification, timely access to quality services and the need for neurodiversity-affirming supports to ensure the wellbeing and inclusion of individuals and their families.

In relation to diagnosis processes, we support the strategy's call for standardisation and consistency in identification screening, outcome, and diagnostic tools. We also stress the importance of developing best practice resources to support families, carers, and support networks through the diagnosis journey in order to provide them with optimum guidance and support.

MFC agrees with the draft strategy's emphasis on improving access to primary health care. We also highlight the need for the integration of primary health care with social and community services, including housing, income support and employment services. This should also include integration with relevant government programs, such as the NDIS, and collaboration between states and territories to ensure a seamless and coordinated approach to service delivery. As a regional service provider, MFC would like to highlight the specific challenges of delivering programs and services in rural and remote areas. We recommend that specific attention be given in the strategy to meeting the needs of Autistic people living outside of major urban centres.

In relation to organisations providing services to people with autism, MFC stresses the importance of improving access to quality, timely, and neurodiversity-affirming supports, especially for people living in rural, regional, and remote areas.

A key strategy to achieve this goal is to develop best practice training and resource materials for service providers. Encouraging greater representation of people with lived experience in delivering supports and services is also crucial in order to increase their effectiveness.

Q. Do you have any other feedback about these Commitments?

MFC supports the commitments outlined in the strategy and believes that by upholding these commitments to governance, research, evidence, and evaluation, this document will help to build a more inclusive and supportive environment for individuals on the autism spectrum and their families.

In particular, MFC recognises the critical importance of establishing a robust governance framework that prioritises accountability, co-leadership, and active involvement of all stakeholders within the autism sector. We welcome the focus on including the voices of people with autism, parents, carers, and professionals in the development and implementation of the strategy.

MFC acknowledges the necessity of fostering autism research and its translation into policies and service delivery. We also support the development of a National Autism Strategy Evidence Framework as a crucial step towards ensuring that interventions and programs are evidence-based and tailored to the specific needs of the autism community.

MFC also welcomes the commitment to establish a robust evaluation plan and reporting mechanism, co-led by Autistic individuals and the autism community. This collaborative approach should help ensure that evaluation processes are inclusive, reflective of diverse perspectives and contribute to the continuous improvement of the National Autism Strategy.

Q. Is there anything you think is missing from the draft National Autism Strategy?

MFC supports the overall aim of the strategy to address the challenges faced by families of children with autism, particularly in rural and remote areas. We welcome the recognition in the strategy of the critical importance of timely access to appropriate assessment, diagnosis, and therapy in addressing children's developmental challenges and improving their outcomes.

We endorse the strategy's recognition of the negative impacts of long delays in accessing services, including missed opportunities for improvement in children's development and increased stress for families. These delays are particularly common in rural and regional areas partly due to workforce shortages and turnover which leads to interruptions in service provision and additional costs. We acknowledge the need for strategies to address practitioner turnover and ensure continuity of care for children and families.

MFC also notes that challenges posed by workforce shortages are often compounded with other access barriers for families in rural and regional areas, such as the higher costs, lower incomes and greater distances which they face when seeking care. As advocates for rural and remote communities, we recognise the importance of providing affordable, timely and suitable services closer to home.

In relation to children with autism, MFC stresses the role of early childhood and school-age teachers as essential allies in identifying potential challenges, and supports efforts to provide them with greater information and resources to support children effectively. Accessible information about developmental challenges for community members is also crucial in raising awareness and promoting understanding.

We note that the gaps between Medicare rebates and the full cost of allied health services, as well as the challenges faced by families in navigating NDIS funding, are issues that require urgent attention. We support efforts to address these gaps and ensure that all families, regardless of their location, have access to the support and services they need.

Q. Is there anything else you want to say about how the Draft National Autism Strategy could be improved?

MFC would like to highlight that workforce restrictions in rural and regional areas significantly impact the provision of autism services. These restrictions include a shortage of specialised professionals such as paediatricians, psychologists, speech therapists and occupational therapists, which limits access to early diagnosis and intervention. High turnover rates among healthcare and education professionals further disrupt continuity of care and affect service guality. Families often have to travel long distances to access services, which can be timeconsuming, costly and logistically challenging, especially for those with limited resources. Limited provider availability also results in longer wait times for assessments and therapies. The Office for the Public Advocate (OPA) found that this was particularly an issue for First Nations peoples. In its report to the Inquiry into the experience of NDIS participants in rural, regional and remote Australia the OPA reported that "implementing NDIS plans in rural and regional locations is made difficult by the scarcity of service or 'thin markets' in these areas..... This scarcity can have a cumulative impact, particularly for people with complex presentations for whom the integration of the full schedule of services is needed for the supports to function as planned, as the absence of one critical provider can destabilise all other aspects of the plan."

Additionally, the cost of accessing services is higher in these areas due to travel expenses and the lack of bulk-billing options, with fewer NDIS providers limiting subsidised services. Inconsistent service delivery due to frequent staff changes and reliance on visiting specialists makes it difficult to maintain stable ongoing relationships with care providers, and the lack of multidisciplinary teams hampers effective treatment. Healthcare and education professionals face professional isolation, with fewer opportunities for development, peer support and collaboration, leading to burnout and exacerbating workforce shortages. Addressing these issues requires targeted strategies to attract and retain professionals, improve service delivery and enhance support networks in these regions, via a place-based approach which responds to the specific needs and priorities of individual communities.

MFC also emphasises the importance of centering the voices and experiences of people with autism in the development and implementation of the strategy. We call on the government to commit to co-delivering the Strategy with people with autism, their families, carers, and support networks. By ensuring active involvement and leadership from the Autistic community, we can create solutions that truly meet their needs and preferences.



We also endorse the commitment to aligning the strategy with other key government strategies and ensuring that it is measurable, accountable, and evidence-based. In the implementation stage of the strategy, MFC stresses the importance of establishing clear outcomes and evaluation mechanisms in order to track progress and identify areas for improvement.

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