

SUBMISSION

**National Guideline for supporting autistic children
and their families**

Submission Title:	National Guideline for supporting autistic children and their families
Date:	25 August 2022
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CARERS QUEENSLAND

The activity and impact of providing care is best understood in terms of its context; as a relationship between two or more individuals, rooted in family, friendship, or community. Caring is a role rarely chosen by most, nor does it discriminate. Children and young people, people of working age and older people, people with disability, people who identify as culturally and linguistically diverse, First Nations Australians, people with diverse bodies, genders, relationships, and sexualities and those living in rural and remote Queensland provide care to family members or friends daily. For some caring is a short-term commitment whilst for others, it is a role that literally lasts a lifetime.

Family and friend carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic medical condition, terminal illness or are frail aged. Carers come from all walks of life.

Carers Queensland is the peak body representing the diverse concerns, needs and interests of caring families in Queensland. Carers Queensland believes that all carers regardless of their age, disability, gender or gender expression, sexual orientation, religion, socioeconomic status, geographical location, or their cultural and linguistic differences should have the same rights, choices and opportunities and be able to enjoy optimum health, social and economic wellbeing and participate in family and community life, employment, and education like other citizens. Carers Queensland's mission is to improve the quality of life of all carers throughout Queensland.

We aspire to provide an independent platform from which to advance the issues and concerns of the 533,200 carers in Queensland and believe our knowledge and expertise in carer issues means we can provide the Government with relevant and trusted information that will ensure that the needs of carers will be recognised, respected, and acted on.

Our submission is informed by national and international peer reviewed data, our own experience as a service provider and the personal and often difficult admissions of carers, those people who provide unpaid care and support.

Introduction

Carers Queensland welcomes the opportunity to comment on the proposed National Guidelines for supporting autistic children and their families. In review of the guidelines, we believe that they provide an excellent basis for supporting autistic children and their families, however, there are multiple limitations.

For this submission the term refers to parent refers to the biological parent, legal guardian, and informal guardians.

Discussion

The guidelines provide a thorough outline for supporting autistic children, but it does not discuss assessment and diagnosis process, which for many families can be an expensive, challenging and disheartening process. There are clear benefits to an autistic diagnosis for children, which include access to supports and funding, however, many families are reporting being unable to access public healthcare for their child's assessment, due to long wait lists, in excess of 14 months in some metro areas. This leaves many, including families who require immediate assistance, with either having no choice but to wait many months on a waitlist, or to access private healthcare professionals. Accessing private healthcare is financially prohibitive for many, however some families choose to do this, in order to access supports for their child, even if that means placing the family under financial stress. A diagnosis is important, as not only does it allow access to support, if that is desired by the child and family, but it also gives the child an understanding of themselves. Children who grow up unaware of their autism lack an understanding of why some behaviours are particularly difficult for them, i.e. social connections. This can lead to feelings of worthlessness and failure, potentially leading to a worsening of mental health problems. This is particularly true for girls, who are significantly less likely to be diagnosed than boys. The lack of diagnosis has a long-lasting impact upon the child, but also upon their family who are unable to access supports or funding to assist their child and the family dynamics.

Recommendation: Carers Queensland would support the inclusion of the assessment and diagnosis process into the National Guidelines for supporting autistic children and their families.

Health co-morbidity is more common in children with autism than in the general population, including genetic, neurological, and mental illness. Common mental health comorbidities are depression, anxiety and obsessive-compulsive disorder. Any comorbidity can cause significant behavioural problems and should be treated by medical professionals in conjunction with any ongoing autism specific supports. Carers report that there is a lack of understanding of autism within the professional health community, which causes behaviours from other medical conditions to not be diagnosed and subsequently treated, and instead being considered an autism symptom. Therefore, autistic children are not getting the full medical or allied health care they require.

Recommendation: Carers Queensland supports the coordination of care from all professions involved in the life of the child. However, we do foresee several privacy and confidentiality concerns, particularly when combined with the common misconceptions about autism.

The physical location of the child also determines the quality and availability of supports. Families living in remote and rural communities are faced with a significant disadvantage when attempting to access supports for their children, due to the inadequacy of local resources available to them. In rural and remote communities there is a lack of adequately qualified professionals in these areas. Families are faced with the option of having to travel long distances to attend appointments with their child,

potentially encountering financial hardship due to the missed work time or significant travel and accommodation costs. This can and does cause low levels of autism screening leading to a late diagnosis, which can have a significantly negative impact on some children. There is evidence to suggest that telehealth, with parental support, can be effective in providing autism support, however this is reliant upon an accessible and stable internet connection.

Recommendation: Carers Queensland fully supports the guidelines recommendation that supports are to be available regardless of the location of the child in practical terms. We believe the guideline should outline how this will be made possible for families.

Education is an important factor to consider when discussing the draft guidelines for supporting autistic children and their families. There are multiple difficulties autistic children, and their families face throughout the Australian education system. Autistic children are faced with many challenges at school from sensory challenges, changing environments, rules and expectations and the additional pressure of making social connections. It is unsurprising that autistic children are twice as likely to be bullied than their peers, particularly during secondary school when differences become more apparent. We believe differences in children should be celebrated in schools instead of punished or outcasted, as is so often the case. To achieve this, a tailored approach to supporting autistic children in school is required. A recent study conducted in Sydney uncovered that 10 out of 22 families reported instances of actual or perceived stigma against their child in primary school.

These families stated that their child was either removed from regular classes, attempts made to remove them from regular classes, while others felt their child had been discriminated against. Parents also spoke of their child or children not being engaged or included in classroom activities and parents being called to collect their child when their behaviour is perceived to be uncontrollable. This action has a two-fold impact. The child is missing out on social and academic outcomes, and the family is potentially being placed into financial difficulty as parents regularly required to leave work to attend to their child. It is apparent that schools are currently not inclusive or well equipped to adequately deal and include autistic children. As a result of this, some families are choosing to home school, feeling there is no alternative for their child. This can raise several difficulties including a lack of social connection, academic outcomes, and relationship strain, as well as the isolation of the child. The inclusivity of schools is essential for the wellbeing of autistic children, and further discussion of this is required in the guidelines to fully support children and families.

Parents of autistic children report high levels of stress and social isolation with poor mental health and a lack of emotional and social supports. Research highlights that autistic children are more likely to display challenging behaviours and aggression than their peers. This behaviour, if not managed, can continue into adulthood, and often has a significant impact upon the child's schooling and family life.

Parents can be subject to aggression and violence from their child. Evidence demonstrates that the presence of aggression, is a significant indicator of carer stress, increased social isolation and feelings of stigmatisation. This is significant because families of autistic children, where no aggression or violence are present, have an increased risk of stress, social isolation, family breakdowns, low confidence levels and a lack of social supports. Therefore, in families where aggression and violence are present, the risk is sufficiently heightened, potentially resulting in family behaviours which further exacerbate the challenging behaviours, creating a long-term worsening of family dynamics. The presence of aggression and violence also notably reduces the availability of outside supports. Supports need to be mindful and supportive of the whole of family, in order to maintain and encourage family wellbeing. Additionally, the guideline would benefit from outlining the rights and support of the caring family.