

**Emerging
Minds.**

Emerging Minds response to Senate Inquiry

Select Committee on Autism

July 2020

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About Emerging Minds

Emerging Minds is a non-profit organisation which has been dedicated to advancing the mental health and social and emotional wellbeing of Australian infants, children, adolescents and their families for over 20 years. Emerging Minds develops mental health policy, services, interventions, training, programs and resources in response to the needs of professionals, children and their families. We partner with family members, national and international organisations to implement evidence-based practice in the Australian context. Emerging Minds is currently responsible for leading the National Workforce Centre for Child Mental Health funded by the Australian Government Department of Health under the National Support for Child and Youth Mental Health Program.

Emerging Minds conceptualises how we can collectively support child mental health in 10 Guiding Principles (next page). These are key elements which consider the child as a whole and underpin the work we do.

We recognise that the best way to support child mental health is through early intervention and prevention. Early in life, early in the life of a problem or early in connection with supports and services. We apply a public health approach to infant and child mental health through increasing child mental health literacy and workforce capacity building, which supports early intervention and prevention as well as responses to child mental health difficulties. The importance of a focus on the mental health of infants and children has been reinforced by contemporary research and there has been a gradual recognition that services need to better address mental health in the early years (Mental Health Australia & KPMG, 2018).

Emerging Minds has a focus on supporting workforces in both child- and adult-focused services in health, social and community sectors. We recognise the importance of the parenting role for adults experiencing vulnerabilities, and the impact of adult vulnerabilities on children's social and emotional wellbeing. In essence the aim is to build the capacity across all workforces to better understand the role they can play in supporting the social and emotional wellbeing and mental health outcomes of children as they develop and grow and transition into adulthood. We are seeking to support a better understanding of early intervention and prevention.

Relevance of this inquiry to Emerging Minds

Child Mental health exists across a continuum, from sound mental health as a resource for life to mental health struggles yet this is not well understood, and most often understood only at the points of mental health difficulties or diagnosis of mental illness. A broader understanding of child mental health literacy is needed. Extensive consultation across sectors including the disability sector has highlighted there is a strong focus on presenting issues and that the social and emotional wellbeing and mental health of a child can be over shadowed by a focus on diagnosis. Emerging Minds is committed to changing this picture and it is through submissions such as this that we call for collective understanding of the role we can all play in early intervention and prevention to support mental health outcomes across the life span.

The range of difficulties which may be experienced by a child or parent with Autism mean the impact of the disorder is intrinsically linked with the mental health and wellbeing of children in families

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affected by Autism. The physical, emotional and cognitive difficulties can make it harder for a child to successfully negotiate their learning and social environments, negatively impacting their development. The stress faced by families, including financial hardship, relationship difficulties and navigating support systems can add to stress in families impacting on parenting, communication connections and supports and therefore on the social and emotional wellbeing of a child.

Greater understanding, along with quality mental health support for children in families affected by Autism can make a long term difference to their mental health outcomes as well as make it easier for children to experience positive and inclusive interactions that can build broader social and supportive networks.

Emerging Minds has a range of freely available resources aimed at building mental health literacy and is currently developing resource for practitioners and organisations which support sectors in their response to support children's mental health where disability is a feature, including Autism.

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Guiding Principles

- 1 Children and their local ecology**
The wellbeing of infants and children depends on their social and environmental contexts, more so than with any other age group. Infant and child mental health is best understood within a framework that accounts for individual child characteristics, family strengths and vulnerabilities, and broader social and economic factors.
- 2 Relationships matter**
Relationships play a central role in children's social and emotional development and mental health. From the time of birth, children need stable and responsive relationships with caring adults.
- 3 Prevention and early intervention**
A focus on preventing or intervening early in the progression of mental health difficulties not only benefits infants and children but also creates a solid foundation for health outcomes later in life, making it a long-term investment in the future of Australian society.
- 4 Strengths and vulnerabilities**
At any point in time, children's mental health is influenced by a mix of strengths and vulnerabilities. Effective practice focuses on enhancing and promoting strengths, while accounting for vulnerabilities.
- 5 Resilience**
Resilience is the ability to recover, adjust to, or grow after an adverse event or period of adversity. The single most important factor for developing resilience in children is the presence of at least one committed and supportive relationship with a parent, caregiver or other adult.
- 6 Trauma informed**
Trauma involves experiences that overwhelm a person's ability to cope. Trauma-informed care is a framework for service delivery based on an understanding of the effect of trauma on individuals, their coping skills and service needs.
- 7 Developmental perspective**
Children are not small adults; they have particular emotional, social and physical capacities and needs. To be effective, service delivery must be designed around infant and child developmental stages.
- 8 Cultural and spiritual identity**
For some children and families, cultural and spiritual identity is central to health and wellbeing. Service provision is more effective if it respects and incorporates service users' cultural and spiritual understandings.
- 9 Children's rights**
Upholding and protecting children's rights is essential to promoting their mental health. It is every adult's responsibility to uphold and fulfil the rights of children.
- 10 Child, family and practitioner voice**
Services designed collaboratively with children, families and practitioners tend to be more effective, more acceptable to the individuals and families using the service, and more relevant to their local context.

10 Guiding Principles of Children's Social and Emotional Wellbeing taken from [Keeping child mental health in mind: A workforce development framework for supporting infants, children and parents.](#)

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Summary of recommendations

The following is a list of general recommendations to integrate support for child mental health into a range of service settings.

Organisational-level elements

The mission and values of the organisation states a commitment to supporting parenting and the social and emotional wellbeing and mental health of infants and children regardless of the entry point in the service system

- Policies and practices aimed at identifying and addressing the needs of parents and their children are in place.
- Child, family voice are considered in service design and delivery

Systems are in place to ensure that data on the number, date of birth and gender of dependent children is routinely collected and recorded.

- This data is collected and collated in such a way that summary-level reports can be used for internal planning purposes and for external stakeholders as required.

Practice is supported by the knowledge that:

Children's daily lives and their mental health are:

- Impacted on by adult's stressors
- Intergenerational issues
- Health
- Ability and disability

Staff have received basic level training in child focused and parent sensitive practice informed by the guiding principles to support infant and child mental health

Staff feel confident and competent to talk about children and parenting

- Parents access services in which staff feel confident and competent to talk with them about their strengths and vulnerabilities in relation to their children and their parenting.

Staff are confident and competent to

- address the social and emotional wellbeing and resilience of children
- work in a child focused parent sensitive way

Conversations about children, parenting and family/kin supports are routine.

Practices and intervention provided nurture:

- Parent-child relationships
- Emotional wellbeing
- Routines that support family functioning
- Communication and meaning making
- Support networks that wrap around the child and family
 - Natural supports
 - Kin, culture and community
 - Professional supports

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Parents are provided with information about and, when necessary, linked to local services that provide parenting or family support appropriate to their specific needs.

- Staff have easy access to up-to-date information about local parenting and family support services.

Family/kin-inclusive appointments are made when appropriate

- Families including children are included in appointments with staff – as and when appropriate to the needs of the service user and the family
- Staff within services feel confident and competent to involve families /kin (including children) in appointments when appropriate.

Family care plans are developed as appropriate

- Parents who may from time to time be temporarily unable to care for their children have the opportunity to develop and maintain a family care plan that outlines information about their children's day-to-day needs and their wishes about care for the children while they are temporarily unable to provide this care.
- Staff feel confident and competent to work in partnership with parents to develop these plans.

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Response to selected Terms of Reference

We have responded below to items of the Inquiry's Terms of Reference which are relevant to child mental health and therefore to Emerging Minds. Our responses are framed with a focus on the social and emotional wellbeing and mental health outcomes as the child develops and transitions into adulthood.

(b) the prevalence of autism in Australia;

- Autism Spectrum Disorder (ASD) is a range of life-long condition that is characterised by profound impairments in social interactions, communication and behaviour (Volkmar et al., 2017). It is considered a brain-based disorder with a strong genetic contribution (Volkmar et al., 2017).
- This condition is associated with high lifelong social and economic costs. It is estimated approximately 56% of people living with ASD do not achieve full independence in adulthood (Taylor & Seltzer, 2011). However, there is considerable variability outcomes for people living with ASD, depending on a range of social and cognitive factors such as capacity , communication skills, intelligence, and language development (Howlin, 2014; Farley & McMahon, 2014).
- Diagnosis of ASD is associated with elevated rates of health conditions, such as seizures (Volkmar et al., 2017). It may also be associated with a range of psychological issues such as victimisation, psychosomatic illness and mental health conditions. These can also increase as children transition into adulthood (Shavelle et al., 2001; Farmer et al., 2014). Mental health conditions may also be more difficult to detect amongst children with ASD, where cognitive or communication difficulties co-exist (Volkmar & Weisner, 2017).
- People living with ASD may be at increased risk for mental health conditions, most notably anxiety and depression. Prevalence estimates for anxiety range from 22% to 84%; (Vasa & Mazurek, 2015) and for depression the prevalence estimates range from 10% to 70% (Chandrasekhar & Sikich, 2015). It's not easy to recognize the presence of anxiety in patients with ASD, because of overlapping symptomatology and altered presentations of symptoms (AADA n.d.)
- Youth with ASD are also at increased risk for being the recipient of bullying, social exclusion and cyber bullying (Heinrich & Myles, 2003).
- Youth with ASD may also be at heightened risk for developing substance use disorder over time (Rengit et al., 2016; Hofvander et al., 2009; Sizoo et al., 2010).

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Implications for child mental health

Responding to identified mental health challenges beyond psychosocial intervention require:

- Access to CBT training for anxiety and depression, adapted to the needs of children and youth with ASD (Zoboski & Storch, 2018).
- Access to social skills training, adapted to the needs of children and youth with ASD.
- Access to health professionals who are trained and can work with comorbidity (ASD and mental health)
- The need to actively plan handover and transition of children with ASD into the adult health services. This can include education services for family members about adult health options and medical summary document for adult health services (Kuhlthau, Warfield, Hurson, Delahaye & Crossman, 2015)

Recommendations:

Prevalence indicates:

- the need for a public health approach to prevention and early intervention method to child mental health
- Child mental health is an economic issue
- Increased workforce awareness surrounding psychological assessments of children and young people with Autism to include ecological assessment.
- Broadening the workforce capacity and understanding of children's behavior as a form of communication and increase understanding of the many diverse ways children with autism communicate and increase access to assistive technologies and communication methods to ensure children are being listened too.

(d.) international best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity.

- Children with a diagnosis of ASD are best supported by a multidisciplinary team (Dillenburger et al. 2014). Consequently, a multidisciplinary approach ensures a comprehensive assessment and understanding of how all aspects of a child's social communication, cognitive and physical development are impacted by their diagnosis.
- Multidisciplinary collaboration is recommended by the United Nations Convention for the Rights of Persons with Disabilities (United Nations, 2007) and adopted by, for example, the UK National Institute for Health and Care Excellence (2013) guidelines for the management of autism in children and young people (Bond & Eldridge, 2012, p.403).
- Generally speaking, youth with ASD can be at heightened risk of developing mental health concerns as they transition to adulthood, due to increased awareness of gaps between social expectations and abilities; and the loss of social support and services associated with primary and secondary school environments (Volmar et al., 2017; Newman et al., 2011).

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- As with other mental health conditions, the risk of developing mental health concerns is related to both genetic and environmental factors. In addition, family circumstances, child's IQ and current age are also risk factors for the development of mental health concerns. (Chandrasekhar & Sikich, 2015; Vasa & Mazurek, 2015). Children with higher cognitive functioning may be more at risk of developing mental health concerns, possibly due to greater awareness of how they differ from others (Volkmar et al, 2017). Similarly, children may experience more difficulties as they age, as social demands increase, highlighting developmental gaps that may have been less obvious when they were younger (Volkmar et al., 2017).
- The UK National Institute for Health and Care Excellence [NICE] (2013; 2016) guideline CG128: recognition, referral and diagnosis and CG170: support and management includes psychosocial strategies to use with children and young people with ASD. The surveillance report (NICE, 2016) highlights specific new evidence and use of various interventions for the core features of autism; behaviour that challenges; life skills and coexisting problems with the aim of improving the outcomes of the child and family relationships, learning, development and wellbeing. This Centre highlights the need for psychosocial strategies for these child and families which need to co-exist alongside the workforce to be trained to improved effectiveness of care, management and support.

Implications for child mental health:

Prevention or intervention strategies used with children at risk of, or experiencing, mental health difficulties need to be appropriate to the developmental level of the individual infant or child, and reflective of approaches that are relevant and applicable to each age group (Australian Infant, Child, Adolescent and Family Mental Health Association, 2011).

Furthermore, effective communication can help those around the child to understand the child's support needs and to offer more effective support around their physical, social and cognitive development. ASD is a condition which can significantly impact a child's development, learning and relationships, early identification of mental health difficulties and psychosocial strategies with a focus on children's strengths and vulnerabilities is important for a child's overall social and emotional wellbeing and relationships with others.

Recommendations:

- Collaboration and integration of multidisciplinary team care models which recognise the lifelong nature and impacts on ASD. These models need to value a comprehensive multidisciplinary approach which includes children's mental health, as critical to achieving positive mental health outcomes for children and youth with ASD.
- All staff working with children and young people with autism should have an understanding of autism; furthermore the workforce development should include children's mental health needs and difficulties to improved effectiveness of care, management and support for children and youth with ASD.

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(I.) the capacity and sustainability of advocacy, self-advocacy and self-determination supports for autistic people, including mechanisms to self-represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities;

- The health and wellbeing of people with disabilities is a human rights issue, which all Australian governments have agreed to address through the [National Disability Strategy](#) (Commonwealth Department of Social Service (2019), Australia's plan for progressively implementing the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2007).
- The Australian Human Rights Commission (n.d) cites UNICEF *"It's About Ability"* (2008; 2009) as a child friendly collection of resources which includes a learning guide and an explanation of the Convention on the Rights of Persons with Disabilities" as way of empower children and young people aged 12–18 to speak out on the convention and become advocates for inclusion in their communities.
- In addition, as a signatory to the United Nations Convention on the Rights of the Child (CRC) (United Nations Human Rights Office of the High Commissioner, 1990), Australia has a responsibility to ensure that children's best interests are reflected in policy and program planning, and that children are widely supported to participate in the decisions that affect their lives.
- Furthermore, children with ASD it is essential to consider the children rights but particularly CRC (United Nations Human Rights Office of the High Commissioner, 1990) Article 23 (children with a disability) has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community, which governments and communities should do all they can to support disabled children and their families. Emerging Minds supports children having input into the discussions and decisions surrounding their mental health. Having child-centred processes in place can also enhance decision-makers' understandings of children's experiences, foster more positive attitudes towards children, and ultimately improve service responses (Moore, 2017).
- The Australian Human Rights Commission (2017) has identified children with mental health issues as being at risk of falling through the service gaps, with poor participation opportunities being a key vulnerability. It is therefore paramount that mental health service delivery is guided by the CRC.

Implications for child mental health:

Upholding and protecting children's rights is essential to promoting their mental health. It is every adult's responsibility to uphold and fulfil the rights of children. Giving children opportunities to be involved in decision-making processes and to freely express their needs can empower them, improve trust, service responses and most importantly a child's social and emotional wellbeing.

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Recommendations:

- In addition to the United Nations Convention on the Rights of Persons with Disabilities for ASD strategy, model of care and service delivery where children are involved also guided by the United Nations Convention on the Rights of the Child.
- To support children with ASD and their families to enable self-advocacy and self-determination there is a need to boost the development and creation of child friendly information and resources.
- Families and their children need to have a voice in service system design and delivery

Concluding comments

Children with developmental disabilities (includes ASD) experience an increased vulnerability to various biological, developmental, psychological and socio-cultural factors that can affect their mental health and wellbeing (Wallander, Dekker, & Koot, 2006). As a result, they live with higher rates of social, emotional, behavioural and mental health difficulties compared to typically developing peers (Brereton, Tonge, & Einfeld, 2006; Dekker, Koot, van der Ende, & Verhulst, 2002; Downs et al., 2018; Dykens, 2000; Dykens et al., 2015; Einfeld, Ellis, & Emerson, 2011; Emerson & Hatton, 2007). These difficulties can impact significantly on children's relationships, morbidity, participation (school, family, work, and the community), and overall quality of life (Einfeld et al., 2006).

Evidence shows that appropriate and timely provision of supports and services for children with developmental disability can alter their developmental trajectory, improve function, reduce the risk of secondary health and psychosocial difficulties, and increase the ability of the family, services and community to support the child and include them in a full and participating life (Early Childhood Outcomes Centre, 2005; RACP, 2013).

Children are not small adults; they have particular emotional, social and physical capacities and needs. To be effective, service delivery must be designed around infant and child developmental stages and disabilities. Emerging Minds is currently working on strategies to integrate child mental health as a vital component of child development in children with developmental disabilities, which can and should be considered within the role of anyone working with children, or with adults who are parents/caregivers. As the focus on preventing or intervening early in the progression of mental health difficulties not only benefits infants and children but also creates a solid foundation for health outcomes later in life, making it a long-term investment in the future of Australian society.

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Additional Material

Framework

The National Workforce Centre for Child Mental Health. (2019). Keeping child mental health in mind: A workforce development framework for supporting infants, children and parents. Adelaide: Emerging Minds. Retrieved from: <https://emergingminds.com.au/resources/workforce-development-framework/>

Online Learning

Emerging Minds has created a learning pathway for a range of service sectors to support child mental health literacy

Emerging Minds is creating a learning pathway for the disability sector that includes engaging with parents to support child mental health

Podcast

[Autism, neurodiversity, and child-centred practice part 1](#)

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