**National Mental Health Commission** 

# National Consultation Summary

March 2024

National Guidelines for including mental health and wellbeing in Early Childhood Health Checks



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# Acknowledgements

The National Mental Health Commission (the Commission) would like to thank everyone who participated in this national consultation. The range of experiences, insights and expertise that has been shared has been instrumental in informing the development of the National Guidelines for including mental health and wellbeing in Early Childhood Health Checks (National Guidelines). We would particularly like to thank those participants with lived experience, including the experiences of caregivers and families, for sharing their stories with us. These perspectives have been invaluable.

## **Acknowledgement of Country**

The Commission acknowledges the traditional custodians of the lands throughout Australia. We pay our respects to their clans, and to the elders, past present and emerging, and acknowledge their continuing connection to land, sea and community.

# Recognition of Lived Experience

We acknowledge the individual and collective contributions of those with a lived and living experience of mental ill-health and suicide, and those who love, have loved and care for them. Each person's journey is unique and a valued contribution to Australia's commitment to mental health suicide prevention systems reform.

## A note on language

The Commission acknowledges that language surrounding mental health and wellbeing can be powerful and, at times, contested. Preferences are often not homogenous across and between groups of people and there is no single consensus on preferred terminology. It is always the Commission's intent to be respectful and use language preferred by most people to whom it refers.

During national consultations the Commission purposefully used a range of terms to describe child and family mental health and wellbeing, including 'social and emotional wellbeing', 'social and emotional development' and 'wellbeing'. This was done to test and refine the most appropriate language for use in the National Guidelines. For the purposes of this summary, the term 'wellbeing' has been used to collectively refer to each of the facets of child and family mental health and wellbeing.

In line with what we heard throughout consultation, language in this summary uses:

- the term 'early childhood health check' to refer to the series of regular appointments that happen between families and health practitioners across all states and territories to discuss how a child is developing.
- the term 'caregivers' to refer to adults who are caring or have cared for a child. The use of the term 'families', refers to the family / caring adult / kinship unit around a child or children. This includes those who do not have a direct caring relationship with the child such as siblings.
- the term 'practitioner' to refer to professionals who conduct early childhood health checks with children and families.
- the term 'coloured book' to refer to Red, Yellow, Green, Purple and Blue Books that are used across the states and territories to record details about a child's health and development from birth to five years of age.
- the term 'LGBTQIA+' as an overarching abbreviation of lesbian, gay, bisexual, transgender, intersex, queer/questioning, and asexual people.

# Overview

The Commission is leading the development of National Guidelines for including mental health and wellbeing in Early Childhood Health Checks (National Guidelines). The Commission is developing the National Guidelines in consultation with key stakeholders in order to:

- support national consistency and the early identification of emotional, learning or developmental difficulties in children;
- expand on the scope of wellbeing aspects covered in existing early childhood health checks (ECHCs);
- · support health professionals to identify current or emerging mental health and wellbeing needs; and
- provide a common framework to discuss child and family health and wellbeing.

This work has been guided by an Advisory Group co-chaired by the Chair of the Commission's Advisory Board, Professor Ngiare Brown and the National Children's Commissioner, Anne Hollonds. The project Advisory Group also includes representation from key stakeholders with expertise in child mental health and wellbeing, primary care, early years research, children with disability, Aboriginal and Torres Strait Islander children and health, and a parent/carer representative (see **Appendix A** for a list of Advisory Group members).

#### Environmental scan

From mid-2022 to early 2023, the Commission conducted an environmental scan based on a review of research, data and evidence, and an analysis of previous, current and planned work relating to wellbeing in ECHCs. This included engaging with key Commonwealth, state and territory governments, and early childhood policy and practice experts.

Key findings from the environmental scan included:

- There is broad agreement that ECHCs provide an opportunity to support all aspects of a child's wellbeing, including social needs and parent/carer wellbeing.
- · Wellbeing is currently included in ECHCs in all jurisdictions, with variation in scope, timing and screening tools used.
- Family attendance at early childhood health checks drops over time as children grow older.
- When ECHCs result in referral for additional supports, families navigate long wait times and high costs.
- ECHCs could provide an opportunity and mechanism to address national and state-level data gaps that exist around early childhood wellbeing.
- There is an opportunity to align ECHCs with the Australian Government's Early Years Strategy (currently in development).
- It is critically important that the language and framing of wellbeing within ECHCs is sensitive to the needs of all families.

#### National consultation

In June 2023, the Commission engaged The Australian Centre for Social Innovation (TACSI) to undertake national consultation to further inform the development of the National Guidelines. The national consultation consisted of an online survey, online consultation workshops, family peer researcher interviews and a focus group with caregivers. Up to 570 participants were consulted as part of the national consultation activities. Further information on the methodology for the national consultation can be found from page 12.

This summary provides an overview of the findings from the national consultation undertaken between July and September 2023.

#### **National consultation findings**

Participants overwhelmingly called for safe and relational experiences, coupled with holistic, family and community centred approaches in ECHCs. This also highlighted the need for increased caregiver awareness of and valuing of the ECHC, both of which would work towards greater equity of access to ECHCs (see **Figure 1**). Factors within the health system were identified that could be addressed to improve experiences and ultimately mental health and wellbeing outcomes for children and their families, including consistent care providers and improved referrals pathways and wait times.



Figure 1. Key consultation themes to enable trusted conversations about wellbeing

# Consultation summary

A number of themes arose through the national consultation (see **Figure 1**). These themes reflect the experiences of national consultation participants, and views about what is needed to enable trusted conversations about wellbeing in ECHCs. Themes are summarised below.

#### Increased awareness, value and access

A key finding throughout consultations was that there is variability in caregivers' knowledge, awareness and perception of the importance of ECHCs. Some caregivers were unaware that ECHCs exist, with many unclear as to their purpose or value. There were also differences in awareness of, and access to, information about ECHCs. For example, we heard that families who are not a child's birth parents often receive limited information, foster families can feel isolated from settings where birth parents receive parenting information, and migrant families do not always receive information explaining ECHCs in their language. Participants also identified that many families were unaware they could access ECHCs for free at maternal, child and family health centres, as opposed to via their GP where gap fees can apply.

Comprehensive and accessible explanations of what happens during a ECHC and why was considered a significant gap. For some families, ECHCs were not explained in ways that reinforce why they are important and how support could be provided to a family during the appointment. The voluntary nature of ECHCs also led to a misunderstanding of their value, with some families assuming they aren't important.



Many parents are very aware of the importance of the immunisation schedule for their child through public health campaigns, apps, save the dates. More work is required to promote the equal importance of developmental screening [as conducted through ECHCs]." National consultation participant

Caregivers wanted a roadmap to help them understand the way children develop, what the assessment points of the ECHC are, and what they can expect from them. Clarity around the process of ECHCs and reinforcing that they are a 'normal' part of every child's early childhood journey was considered particularly important for families who have had previous contact with the child protection system.

The importance of clear communication regarding what to expect after the ECHC was highlighted including what support is available within the community, and an understanding of available referral pathways. There was a clear desire for personalised, responsive follow-up, where professionals are readily accessible to answer questions and provide assistance.

It was acknowledged that there are a number of families across Australia who experience compounding challenges that impact their ability to engage in ECHCs. For example, participants described that families facing complex challenges related to housing and finances did not have the time to prioritise attending ECHCs. It was thought that those experiencing multiple challenges, require higher levels of support, follow up and advocacy. These challenges included:

- poverty
- family and domestic violence
- substance use
- caregivers who have had adverse childhood experiences
- caregivers who have experienced mental ill-health and/or trauma
- trauma that has been part of the experiences leading to seeking asylum and/or obtaining refugee status
- social isolation and limited support networks

· racism and systemic discrimination.

### Family and community friendly locations

The importance of conducting ECHCs in family and community friendly locations was consistently highlighted. Caregivers reported that they would be more likely to attend an ECHC if it was easily accessible and they had more choice about the location and time of ECHCs. It was noted that there are many places in local communities that are accessible by foot, where families often go, and would feel safe and comfortable to have a conversation about wellbeing. Such locations included outdoor spaces, parks, libraries, schools, pharmacies, workplaces or at home (if agreed to with a family).



creating safe and welcoming environments, fostering an atmosphere where all families feel comfortable." National consultation participant

It was also reported that services having a presence in the community would lead to stronger trusting relationships with community members and reduced stigma around conversations about wellbeing (particularly for rural and remote areas).

For some families, playgroups were thought to be a safe environment where consistent relationships are formed over time. Caregivers also trusted early childhood educators and their ability to spot changes in their child's pattern of behaviour. Participants identified that conducting ECHCs in the context of playgroups could better integrate caregivers, early childhood educators and health practitioners. It was reported that caregivers could have a deeper, more engaged conversation when their children were playing or occupied. It was noted that it can be difficult for caregivers to have open and transparent conversations about wellbeing when toddlers or young children are in the room as they can understand and follow the conversation.

Participants said that having online, phone or hybrid conversations as an alternate option to in-person helped parents feel like they could attend the check despite any challenges on the day (for example, transport not being available or unexpected illness). Participants expressed the importance of choice, acknowledging not all families would have access to video-conferencing technology or strong internet for a tele-health appointment, particularly in rural and remote areas where mobile service might be more readily available than internet.

A number of challenges associated with alternate locations for offering ECHCs were also raised:

- Playgroups often have underrepresentation of lower socioeconomic families and those experiencing challenges. It was also reported that foster families are less likely to attend playgroups, and that for some, playgroups can be less accessible due to the stigma of poverty.
- Scope to conduct a holistic ECHC about a families' wellbeing in early childhood education settings may be limited if caregivers are not present.
- There is an additional burden placed on early childhood educators if they were to support or conduct certain elements
  of the ECHCs, noting limitations to their professional roles, training and experience.
- There are limited existing connections between healthcare practitioners and some early childhood education settings.

#### Holistic approaches

Participants expressed the need for including wellbeing in ECHCs to take a holistic, ecological approach to child and family wellbeing, acknowledging the environments and relationships that influence wellbeing.

Caregivers preferred conversations about their everyday experiences with their child (such as sleeping and eating habits and family and social connections) and thought that this would assist the practitioner to create a fuller picture of a families' wellbeing, as well as build familiarity and trust. It was also felt that prescribed questions or topics can take away the ability of the practitioner to deeply listen.

Caregivers spoke about the flow on effects of the cost of living and financial pressures on the wellbeing of the family, and the need for support with awareness and navigation of other government services (such as parental payments from Centrelink and accessing disability support services). Housing insecurity was also raised as a concern for families.

"

The importance of having a healthy environment within a home to ensure that I can best provide for my children. Maintaining that home financially is important as that affects everything around."

National consultation participant

It was suggested that every family attending an ECHC should be asked about these kinds of needs or support areas (such as housing insecurity and cost of living pressures) as this would normalise the subject matter. Participants said that a trusted relationship with a practitioner was critical to have conversations about such sensitive subject matter.

It was suggested that existing ECHCs tend to focus on the child in-question and rarely expand focus to supporting the wellbeing of the child's siblings and the overall family unit. Participants also reported there is an assumption that caregivers who have raised more than one child would require less support because they have already been through the early childhood journey with another child.



each one of my three girls are completely different - what you learnt for one doesn't apply to the other." National consultation participant

Participants expressed the need for practitioners to focus on the wellbeing of caregivers in order to understand the support required for a child's wellbeing. It was noted that a child's wellbeing is strongly impacted by family member's mental health challenges, substance use and trauma histories, and these may go undiagnosed or not addressed. However, participants raised that caregivers experiencing family and domestic violence may not feel comfortable disclosing or discussing this in the presence of their children and consideration would need to be given to how to engage in these conversations safely and appropriately. Further, some caregivers might not wish to discuss wellbeing in the presence of other carers who are present at the ECHC, for example, if two parents are separated and attend the check together.

## Safe experiences

For open and honest conversations about wellbeing to occur, all families need ECHCs to be a safe experience. Not feeling culturally safe during the ECHC was reported as a significant barrier to attendance. Participants described that language and conversations are often based around a Western understanding of wellness and family. A gap in cultural safety in non-Aboriginal practitioners was reported, leading to experiences of racism and judgement for some Aboriginal and Torres Strait Islander caregivers.



[she] felt the way of parenting wasn't in line with her community, but [she] felt she needed to go along with it because of [the] practitioner's behaviour and attitudes." National consultation participant

Some caregivers had also experienced criticism around feeding practices, wrapping their children (for example, swaddling), sleep, community and social supports, and circumcision. A number of families experienced friction and challenges trying to reconcile how children were raised in their culture, with Western practices and standards sometimes considered the norm in Australia.



Culture and traditions are very important regarding raising children and even if we are now living in the Western world, we should not neglect our culture and home traditions as they are there for survival and support." National consultation participant

Participants reported there is little to no support for non-Western families to understand or be supported during diagnoses or conversations about a child's mental health, especially when conceptions of mental health and wellbeing differ from mainstream understandings. This often led to confusion and distress in families.

For caregivers who have experienced out of home care themselves as a child, and for families who have had child protection notifications, the idea of a "check" created anxiety and fear about their child being removed. Participants advised this could result in sharing minimal information or withholding issues during ECHCs to minimise the potential of any scrutiny.

Participants identified the need for practitioners to have the skills to create safety for families to talk about challenges, and not feel judged or shamed if a need was identified. It was thought that practitioners need to tailor the conversation to each family. The importance of using clear and simple language, reducing the use of academic or medical jargon, nationally consistent use of interpreters and translation approaches were all highlighted.

#### Relational experiences

Building rapport through ongoing, genuine relationships was highlighted as crucial in creating a trusting, safe partnership between practitioners and caregivers.

A practitioner's use of language was thought to play a critical role in rapport building. Appreciating the nuances and interpretations of language was also seen as important, as well as using non-clinical language.



definitions and language is really important. Wellbeing is a loaded term that means lots of things to lots of different people" National consultation participant

Caregivers wanted a genuine conversation that asked about their wellbeing, rather than solely asking about the child. They wanted the conversation to feel more personal, to be mindful of judgements or critical comments, and to recognise that every child is different. Having a conversation beyond the 'coloured book' or a 'checklist' was seen as critical. Caregivers wanted to be able to direct conversations and choose the topics that were important or challenging for them at that time. Participants expressed a need for practitioners to be responsive to families' needs and gauge stress levels for the family throughout the ECHC.

Caregivers explained how they lost trust in providers when they were not being heard, and often felt shamed or judged, for example around feeding practices. Caregivers also expressed they felt that they had a good sense of when something was not right with their child, but this was often dismissed.



When parents had a sense that something wasn't ok, they were often told that it was the result of their anxiety and dismissed and then found out 18 months later that there was actually something wrong."

National consultation participant

Caregivers wanted the ability to receive advice from a practitioner but also to give their input. The value of the workforce reflecting the community they served was raised as key to building trust and connections. The challenges that people experiencing family and domestic violence might have in building trust, especially in conversations about wellbeing, was also raised.

#### System level factors

Many factors within the health system were identified that could better support the inclusion of wellbeing in ECHCs, including the desire for consistent care providers and improved referrals pathways and wait times.

Families expressed a desire to see the same practitioner from pregnancy through to early childhood, and the same practitioner again if they have more children. This was particularly important for Aboriginal and Torres Strait Islander families, and those with a history of trauma.

Participants identified that having no regular primary care clinician could act as a barrier for families to attend an ECHC. It was reported that some families cannot afford to see a GP, and instead are seeing pharmacists or attending urgent care centres, and do not experience continuity in care and sharing of information.

Participants described problems with siloed ways of working across the health system. Participants perceived crossorganisational territorialism and mistrust between organisations as common, resulting in information not being shared. Participants identified a lack of practitioner awareness of other practitioners and services could also negatively impact family experiences.

Long wait times for specialists and other services were identified as challenging for families. This was noted as being particularly significant in rural and remote areas. Participants said that referral pathways are not always in place for children and there are not always services available to diagnose or provide intervention.



often families tell us they feel overwhelmed, not only in their efforts to support the needs of their child/children, but also on navigating the various systems and services that they must." National consultation participant

# National consultation methodology

# Online survey

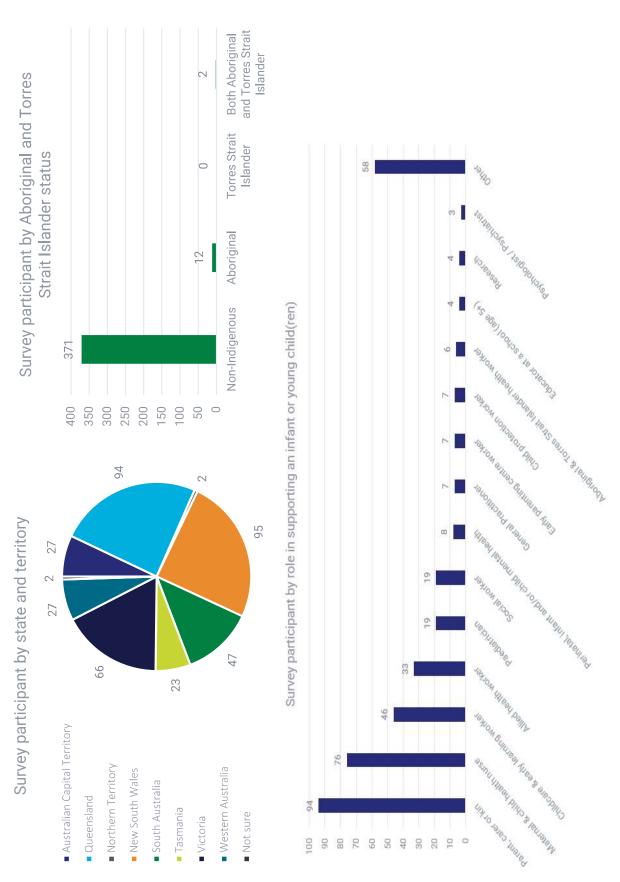
The online survey ran from 27 July to 20 August 2023 and received a total of 413 responses. The survey consisted of 17 questions and was developed in line with the initial findings from the environmental scan.

The survey explored:

- the importance of including wellbeing in ECHCs
- who should be involved in conducting an ECHC
- where ECHCs should take place
- which topic areas should be included
- barriers and motivations to attending ECHCs.

The survey was aimed at people who are involved in, or who have experience of, ECHCs. The survey was anonymous but included some optional demographic questions. See **Infographic 1** for a summary of key survey participant demographic information of the survey participants who provided a response to the demographic questions

Infographic 1. Summary of key survey participant demographic information



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## Online consultation workshops

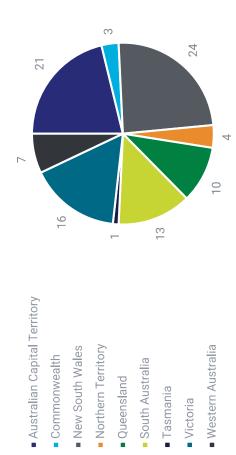
Thirteen consultation workshops were held between August and September 2023. The workshops provided an opportunity to deepen the conversation on how mental health and wellbeing could be included in ECHCs and what the conversations should cover. This included exploring where ECHCs should take place and who should be conducting the mental health and wellbeing components of them. Participants were asked to share their experiences of the ECHC and what they would like to see in the National Guidelines.

The Commission used its existing networks and knowledge of the sector to identify organisations and key experts to participate in the consultation workshops, including those involved in discussions as part of the environmental scan and participants from the online survey who provided their contact details for further engagement. Consultations were also promoted through the Commission's newsletter and social media accounts, as well as through the Advisory Group and TACSI's networks to ensure reach beyond existing networks.

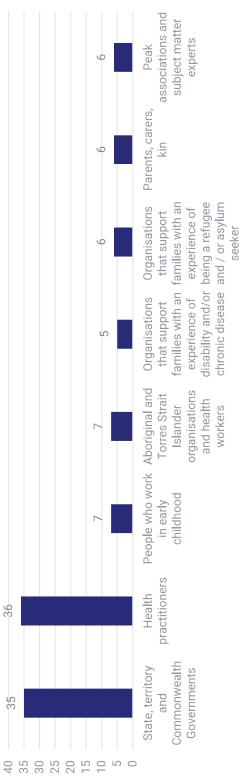
A total of 108 participants attended the online consultation workshops, with participating organisations ranging from NGO's, universities, research institutes, private and public health and mental health services, Commonwealth, state and territory government departments, peak bodies and professional associations. See **Infographic 2** for a summary of key workshop participant demographic information. To ensure anonymity some demographic information was not collected from participants in the parents, carers and kin workshop

Infographic 2. Summary of key workshop participant demographic information

Workshop participant by state and territory







## Family Peer Researcher interviews and focus group

#### **Family Peer Researcher interviews**

Eight caregivers from New South Wales, South Australia, Northern Territory and Victoria were recruited by TACSI to conduct interviews with caregivers and families in their networks. Family peer researchers were supported by TACSI with training and skill development in conducting interviews. The purpose of the interviews was to enable deep and contextual in-community conversations about ECHCs and to capture the voices of families with diverse experiences from across Australia. This peer-to-peer approach is an established research model utilised by TACSI and allowed the Commission to access hard-to-reach populations and increase the diversity of caregiver and family voices.

Experiences of family peer researchers and their networks of interviewees included:

- LGBTQIA+ family experiences
- Migrant family experiences
- Young parent experiences
- Single and multiple child families
- Single parent and two parent families
- · Families with experiences of financial hardship
- Experiences of family and domestic violence
- Experiences of neurodiversity and/or disability
- Life in metropolitan and rural areas.

A total of 41 family peer researcher interviews were conducted in September 2023. The interviews took between 45-90 minutes, with four interviews conducted in either Farsi or Mandarin, and the notes translated by the interviewer.

#### Aboriginal young mums focus group

To ensure strong representation of First Nations voices an Aboriginal Young Mums focus group was conducted. TACSI connected with an Aboriginal Young Mums group who were supported to run an in-person focus group during one of their regular sessions.

This focus group was hosted by an Aboriginal woman who had trusted relationships with the young mothers, creating safety and space for honesty about what was working and what needed improvement in ECHCs. Eight young mums, who were regular attendees at the group, were part of the yarn and shared their experiences of pregnancy, antenatal and postnatal care, what supported or diminished their wellbeing, their experiences of ECHCs and what could be done better in the future.

#### Limitations

Whilst every effort was made to ensure national representation, there was some difference in the level of representation across states and territories in each stream of data collection. Additionally, while approximately 150 people were spoken to as part of the consultation workshops and family peer researcher interviews, this is not representative of all families' experiences in Australia.

Known limitations include:

- Participants were adults (no children were recruited into the consultation).
- Only two participants identified as fathers.
- Representation of GPs in the consultation workshops was lower than other practitioner groups.

•	No interpreters were available during the workshops. However, all participants were invited to advise of any accessibility needs prior to the workshop and these were accommodated where possible, for example by participating via the chat function in Zoom rather than using audio.

# Appendix A

# National Guidelines Advisory Group members

- Professor Ngiare Brown, co-chair General Practitioner and Chair of the National Mental Health Commission Advisory Board
- Anne Hollonds, co-chair National Children's Commissioner
- Kate Armstrong National Aboriginal Community Controlled Health Organisation (NACCHO)
- Representative Secretariat of the National Aboriginal and Islander Child Care (SNAICC)
- Professor Valsamma Eapen UNSW, Academic Unit of Child Psychiatry Southwest Sydney (AUCS), BestSTART
- · Bronwyn Field Department of Health and Aged Care
- Emily Humphreys Parent/carer representative
- Associate Professor Nitin Kapur Paediatrician, Royal Australasian College of Physicians (RACP)
- Brad Morgan Emerging Minds
- Professor Frank Oberklaid Paediatrician, Murdoch Children's Research Institute
- · Sharon O'Mara Children and Young People with Disability Australia
- Dr Marshall Watson Psychiatrist, Telethon Kids Institute
- Dr Nicole White General Practitioner representative
- Louise Wightman Maternal Child and Family Health Nurses Australia

