

Supporting families while they wait for a health care service

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What is this resource about?

Primary health care practitioners in Australia often refer children and their families to services for allied health or specialised care. Wait times for these services can be long, ranging from weeks to years (McGill, Crowe, & Mcleod, 2020; Mulraney et al., 2021). This resource explores the impacts of long waiting times on children and families' mental health, and provides guidance on how to support families who are waiting for a service. This paper is informed by the available research as well as consultations with parents.¹

Who is this resource for?

This resource is for health care practitioners working with families who have children aged 0–12 years who are waiting for a health care service. It focuses on two main groups:

- primary health care practitioners (e.g. general practitioners; infant, child and maternal health nurses; and early childhood education and care workers) who refer families to specialised health care services
- health care practitioners who receive referrals for a child to attend their service (e.g. paediatricians, psychiatrists, psychologists, allied health professionals).

Key messages

- Extended health care waitlists can be harmful for children. They can negatively impact current symptoms, mental health and wellbeing, and school and family functioning.
- Long wait times for a service can negatively impact the child's family, potentially causing stress and anxiety.
- Parents identify health care professionals as a potential support for themselves and their children during the waiting period.

¹ Parent consultations were conducted via email, with 10 anonymous parents providing responses to a series of questions about their child's experience while on a waiting list.



- Health care practitioners can support families on a waitlist in a range of ways, such as by organising ongoing contact with families, supporting child and parental mental health concerns, and providing families with further information and resources.

A note on terminology and waitlists

Various words are used when referring to patients waiting for a service. Terminology includes:

- **waitlist** which is simply another term for waiting list; and
- **extended waitlist** which does not have a predefined time period according to the literature; however, in the context of this resource, extended wait refers to periods of waiting longer than two weeks.

Wait time, as referred to in this resource, is defined as: the time spent waiting for a future, scheduled appointment with a health service.

There are various stages where a patient might experience a waiting period, including:

- the time taken for a primary health care practitioner to write and send a referral to a suitable service
- being placed on a waitlist until an appointment becomes available for a specialist/allied health care professional due to no current availability
- between the time a referral is sent to a service and when the patient hears back about the referral outcome and scheduled appointment; and/or
- being booked in for an appointment but experiencing an extended wait time until the scheduled appointment date.

Introduction

Waiting for access to children's health services is a common occurrence in the Australian health care system. Extended wait times can negatively affect children's mental health and wellbeing (e.g. anxiety; increased risk of harm or hospitalisation) and their symptoms may worsen as they wait for the care they require (Schraeder & Reid, 2015; Semovski, King, & Stewart, 2021). Children and families report feelings of frustration, fear and uncertainty during the waiting period (Rittenmeyer, Huffman, & Godfrey, 2014).

Parents can feel overwhelmed, stressed and anxious as they wait for a service for their child. Families who experience a longer wait period are typically more dissatisfied with the service (King, Cathers, King, & Rosenbaum, 2001) and long waiting times can stop some families from seeking help for their child's mental health concern altogether (Reardon et al., 2017). The National Children's Mental Health and Wellbeing Strategy (Australian Government, 2021) highlighted the critical need for children on extended waitlists for assessment or treatment to be better supported by practitioners.

Australian health service waiting lists

Wait time lengths vary between public and private health services, and metropolitan and rural/regional areas. Broadly speaking, service waitlists range from one month to more than three months. Some Australian studies have reported wait times of over 12 months for both adults and children (McGill et al., 2020). The wait times for a paediatrician in the public health system are often longer than in private health (Hiscock, Gulenc, Effron, & Freed, 2018), with private paediatricians seeing 90% of patients within three months, compared to 70% in public settings. One Australian study found that paediatricians had an average wait time of 44 days (Mulraney et al., 2021), although length of wait time varies depending on the nature of the condition the child presents with (Hiscock et al., 2018). Practitioner reports suggest that children with physical health conditions are typically seen sooner than children with developmental and behavioural conditions (Hiscock et al., 2018).

Long wait times for child mental health professionals have also been reported, with median wait times for private psychologists and psychiatrists ranging from 34 to 41 days (Mulraney et al., 2021). An Australian study found that in 2017–18, parents reported long delays in scheduling appointments with psychiatrists and community-based child and adolescent mental health services (CAMHS) (Hiscock et al., 2020). These delays were particularly common for families living in rural or regional areas where there is a lack of available mental health services, especially after school and outside work hours (Hiscock et al., 2020; Mulraney et al., 2021).



Factors contributing to extended waitlists

Various factors influence service wait times – for example, paediatricians may limit appointments for children with developmental or behavioural problems as such cases tend to be more complex and time consuming (Hiscock et al., 2018).

Private mental health service costs can be unaffordable for some families (Mulraney et al., 2021) with cost often cited as a reason for not accessing mental health services (Reardon et al., 2017). Many families attempt to access more affordable, publicly available specialist and allied health options, which increases the number of families competing for these services and therefore lengthens wait times (Hiscock et al., 2020).

The impacts of waiting for a service on children

Evidence suggests that extended wait times can have a range of negative impacts on children's mental health including increased distress, anxiety (Schraeder & Reid, 2015) and the further deterioration of pre-existing mental health issues (Kreindler, 2008). Extended waitlists can be incredibly disheartening for children and their families (Australian Government, 2021) and long waiting times have been identified as one of the most common barriers to children receiving effective mental health care (Paton et al., 2021).

Children awaiting service for a physical health concern can experience negative impacts if their physical condition declines before their appointment (Davies, 1999). Further, these children may report mental health and wellbeing difficulties – for example, a child with severe asthma may report experiencing anxiety and distress when participating in school sports classes.

Having to wait a long time to access services can negatively affect children's underlying conditions, mental health, quality of life, school and family functioning (Hiscock et al., 2018; Semovski et al., 2021). Their symptoms may worsen and long-term or lifelong complications may develop as a result (Clark et al., 2018; McGill et al., 2020). Parent consultations and research literature revealed the following further mental health and psychosocial impacts that children may experience while waiting an extended period to access a health service:

- **Anxiety and depression.** While waiting for a service (particularly a time-sensitive service), children can experience worsening mental health and reduced quality of life (Gagliardi et al., 2021).
- **Feelings of isolation.** Parents reported that children may refuse to participate in social activities and have difficulty making and maintaining friendships (McGill et al., 2020). Children may also disengage from their siblings and the rest of their family.
- **School refusal and disconnection from learning.** Children may disengage from their school life or have their schooling interrupted (Wooster, 2008), decreasing learning outcomes and furthering feelings of loneliness and isolation.
- **Decline in psychological wellbeing** (Lynch et al., 2008). Parents reported that children express increased feelings of hopelessness and a decreased sense of self-worth.



Impacts of waiting for a service on families

Parental and family wellbeing are critical for children's wellbeing (Rioseco, Warren, & Daragnova, 2020) so it is worth considering the potential impacts of an extended waitlist on all family members. Parents can experience various challenges while their child waits for a health care service. As more time is spent on a waitlist, families can lose hope and become less likely to engage with specialised services (Schraeder & Reid, 2015). York and colleagues (2004) found that the longer a family waited between a referral and their first CAMHS appointment, the more likely they were to fail to attend this initial appointment.

Families have also reported the following effects of having a child on an extended waitlist for health care services:

- **Overwhelm and exhaustion.** Parents report feeling exhausted due to the effort and resources it takes to find an appropriate service or clinician (Hiscock et al., 2020). Navigating large amounts of new information relating to their child and their concern can be a difficult process.
- **Frustration.** Once a suitable service has been found, parents report feelings of dissatisfaction at treatment delays (Hiscock et al., 2020). As the waiting period progresses, parents feel increasingly frustrated that their child is not receiving the help they need.
- **Helplessness and guilt** (Boulter & Rickwood, 2013). Parents experience a sense of helplessness as they feel they cannot adequately support their child during this waiting time. Parents also describe feelings of guilt at not being able to provide timely care for their child (e.g. not being able to afford a private health service that may have shorter wait times).
- **Stress and anxiety.** Parents are concerned about how to best support their child while on a waitlist. They may also worry about their child's prognosis and the uncertainty of future outcomes (Crouch, Reardon, Farrington, Glover, & Creswell, 2019).
- **Isolation** (Hiscock et al., 2020). Parents can feel a lack of support from family and friends. They may not understand the child's concern and are therefore unable to appropriately support the parents.
- **Increased pressure on the family.** There are significant impacts on family structure and cohesiveness, and relationships between family members can be negatively affected (McGill et al., 2020).

What can practitioners do? Supporting families experiencing long waiting times for a children's health care service

This section includes a range of strategies to assist practitioners to support families while on an extended waitlist. Practice recommendations are drawn from available research and consultations with parents. Although some considerations are relevant to both groups of practitioners, certain practice solutions might be more relevant to primary care practitioners (i.e. the referrers) or specialist or allied health practitioners (i.e. the receivers of the referral). Children's safety is always the first consideration – if you identify any immediate or escalating risk to children's mental health or wellbeing, take appropriate action.

Primary health care practitioners referring children to a specialist or allied health care service

Explore potential impacts of waiting for a health care service and the need for further support

You may find it challenging to identify whether a family is at a risk of experiencing negative impacts while waiting long periods for a service and importantly, who might potentially disengage from seeking help. It can be helpful to ask families questions about themselves, their child and how they are managing during the waiting period. For example, you could try:

- How are you feeling while you are waiting to hear back from [the service]?
- How do you think your child is feeling? How has their [behaviour of concern/issue] been and has it changed?
- Do you have any concerns about your child and [their concern] while they wait to see the specialist?
- Is your child's [concern] impacting your family in any way? What is helping you and your family cope?
- How is [sibling's] relationship with [the child]? Does [the child's] behaviour worry [sibling]?
- Do you have extended family or friends who can support you during this time?
- Have you found any helpful information or resources?



Schedule regular contact with children and families

Having regular, scheduled contact with children and their families may help to alleviate mental health and wellbeing difficulties (Crouch et al., 2019). If appropriate, reassure parents that you are available for ongoing appointments, or you might wish to offer brief check-ins via phone. If families prefer regular consultations with you, it can be helpful to ask them to note down any concerns they have prior to each session. You can then work with the family to address these and any ongoing issues they may be facing.

Make a plan with the family

Parents have reported that contact and support from professionals during the wait for a service helps make getting through this time easier (Crouch et al., 2019). You can work with the family to develop a plan together of how to best manage the waiting period. This plan could include what the key issues might be, where families can look for help and how regular your contact with the family should be. You can tailor this approach to the family you are supporting to create a plan that addresses their specific needs during the waiting period.

Remind families of upcoming appointments with health care services

Since dropout rates increase alongside waiting times for an initial appointment, families you refer may be less likely to attend their first appointment the longer they have to wait (York, Anderson, & Zwi, 2004). You can reduce the chance of a family disengaging from a service by calling or messaging them prior to their first appointment to remind them that it's coming up. This can serve both as a reminder and as encouragement for the family to attend the service and access the help they need for their child.

Encourage parents to advocate for their child

It can be helpful to encourage parents to advocate for their child when seeking a service. For example, if a parent does not hear back from a service once a referral has been sent, you could prompt them to call and find out what is happening. You may wish to help parents come up with a list of questions or concerns that they can raise with the service they have been referred to. As a health professional, you are well positioned to help the family understand the health system and services they are navigating. You can share insights about how services are run to help families understand their options – for example, you can explain to parents that when booking an appointment for their child they can ask to be contacted if an appointment becomes available at short notice.

Support children's mental health concerns

If parents express concern about their child's mental health and wellbeing, enquire about the specific issues causing this concern. Provide families with information or resources they can access to support their child's mental health. You can also recommend strategies based on your professional knowledge or that you have seen other families use, which may address the child's social and emotional wellbeing concerns. You can encourage parents to monitor their child's situation and provide them with interim services to access if their concerns escalate. Take appropriate action if you identify a safety issue.



Address parents' mental health concerns

It is important to consider parents' wellbeing as they wait for their child to be seen by a service. You might explore how they are feeling and how their child's health concerns are affecting them during the long wait time (refer to previous example questions). If parents report mental health difficulties such as anxiety or distress, assess their concerns further, and if appropriate encourage them to access further support including mental health resources (listed under 'Further resources', following).

You can also work with parents to identify and reach out to informal supports (e.g. extended family, friends and/or teachers) that may be available to them. They may also find it helpful to connect online with parents who are experiencing a similar situation. Informal social supports can often provide sustained assistance to families beyond what formal supports and services are able to offer.

Health care practitioners receiving the referral

Provide information about your service and wait times to families

Families report that it would be helpful to have communication from a service after their referral has been received. Specialist or allied health services can reach out to families to confirm that a referral has been received and to offer information on the service (e.g. length or cost of appointment; what might happen in the first appointment). Initial contact may be a short telephone call, email or text message to notify parents that the referral has been received and is being processed. Any written information should be in plain and simple language that's easy for parents to understand.

Knowing what to expect in terms of length of waiting time, even if it is an estimate, and what to expect from a service can help families to better prepare for what is ahead for their child (Gagliardi et al., 2021). So, if a parent raises questions about waiting times you could provide a general estimate of how long things might take, while also specifying that times may vary.

Provide information about managing the impact of wait times

Families waiting for services may struggle to manage their child's condition, particularly before a diagnosis has been made, and follow-up treatment and management has started. Parents report that information and coping strategies would help them in managing their child's behaviour and symptoms during the waiting period (Crouch et al., 2019; Gagliardi et al., 2021). It can be helpful for your service to offer information and resources at various stages of the waiting period, providing families ongoing support and keeping them engaged with the service. Examples of what to share include:

- a factsheet addressing common parental concerns
- information on general strategies parents can use to support their child
- information about available self-directed tools to promote positive lifestyle behaviours and manage common symptoms
- links to self-help resources that families can use if they feel they need additional support (refer to 'Further resources' following for some suggestions).



Further resources

The following are links to resources and services that can support families during an extended wait period.

Parenting helplines

<https://kidshelpline.com.au/parents/issues>

Parenting helplines are [free, confidential phone services for parents](#) that provide anonymous counselling and support on parenting issues. Visit the Kids Helpline website for the [parent helpline number to call in your state or territory](#).

Raising Children Network (RCN)

<https://raisingchildren.net.au>

The Raising Children Network is a [comprehensive and trusted online resource for parenting information](#) and includes information on children's health and wellbeing across the ages. RCN includes videos, factsheets and downloadable toolkits on child development, behavioural problems and mental health issues. The website also includes information about parental mental health and wellbeing, as well as tips for managing child behaviour and development.

Beyond Blue

<https://www.beyondblue.org.au>

Beyond Blue provides a range of [services and supports for people affected by mental health concerns](#) such as anxiety, depression or suicide.

Beyond Blue Healthy Families

<https://healthyfamilies.beyondblue.org.au>

This website provides [information for parents on child mental health](#) and how to promote strong mental health in their child. Beyond Blue also has resources for caregivers to support their own mental health.

Emerging Minds Families

<https://emergingminds.com.au/families>

Emerging Minds Families provides a range of [mental health resources including fact sheets and toolkits](#) for families to support their child's mental health and wellbeing.

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