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Research Summary



MIGHTY MINDS

Mighty Minds: Co-design of an evidence-informed approach to promote the mental health of children living with disability and chronic health conditions on the Melbourne Children's campus

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Children and young people living with disability and chronic health conditions are at increased risk for mental health difficulties including anxiety, depression, suicidality, and posttraumatic stress disorder.[1-4] Despite having regular interactions with the healthcare system, the mental health care needs of many of these children and their families remain unmet.[5-7] Through the Mighty Minds study, we sought to better understand how The Royal Children's Hospital (RCH) can more effectively support the mental health and wellbeing of these children and their families.

The Mighty Minds Study

We partnered with six children and young people with disability or chronic health conditions and 13 parents/caregivers through two Lived Experience Advisory Groups (LEAGs). We then invited children and young people living with disability or chronic health conditions who regularly access care through the RCH (twice or more per year), parents/caregivers, and RCH clinicians to participate in an interview or online survey. We asked participants about their experiences of receiving (or providing) mental health care for children, young people and families at the hospital. This included discussion about things that positively support mental health and wellbeing, as well as things that could be improved.

Who participated in the Mighty Minds study?



16 children and young people

- Average age of 12.8 years (range 6 to 18 years)
- All born in Australia
- Diverse range of disabilities & chronic health conditions e.g., cerebral palsy, Crohn's disease, genetic conditions



30 parents/caregivers

- Majority were mothers & were Australian born
- Caring for children with a diverse range of disabilities & chronic health conditions e.g., intellectual disability, cerebral palsy, allergic disease



22 RCH clinicians

- Medical, nursing & allied health disciplines
- Several different departments & varying levels of experience

Figure 1. Summary of who participated in the Mighty Minds research project.

Co-design of recommendations

Drawing on data from the surveys and interviews and in partnership with our LEAGs, we co-designed recommendations to strengthen the capacity of the RCH to provide trauma-informed, family-centred mental health care. These practical recommendations include systems- and clinician-level strategies to address key barriers to mental health and wellbeing care and support at the RCH.

Overview of what our research told us

- Good practices and processes that support mental health and wellbeing exist; however, these occur inconsistently across the hospital departments. For example, the support received often depends on who you see (the clinician and department), what disability or chronic health condition you have, and the family's ability to advocate.
- Structural issues (e.g., no central point of information about existing mental health services, limited mental health support specifically for children with physical and intellectual disability, and chronic health conditions) make it difficult for both clinicians and families to find and access appropriate mental health services, both inside and outside of the hospital.
- Simple relational aspects of care are very important. For example, relating to the child as a person, not only treating their disability or health condition, using strengths-based language, regular check-ins about overall wellbeing with children and families.
- The focus of care should extend beyond child mental health and wellbeing to also include the mental health and wellbeing of parents and families.

Recommendations - key priority areas

Based on the findings of the Mighty Minds study, recommendations for improving the mental health and wellbeing of children and young people with disability and chronic health conditions and their families have been developed. Five priority areas were identified, each with its own supporting rationale and recommended actions, as outlined on pp.5-8. These priority areas have informed the development of a framework for mental health-informed care (Figure 2). Mental health-informed care involves access to health care that recognises and responds to both the physical and mental health needs of children and young people.

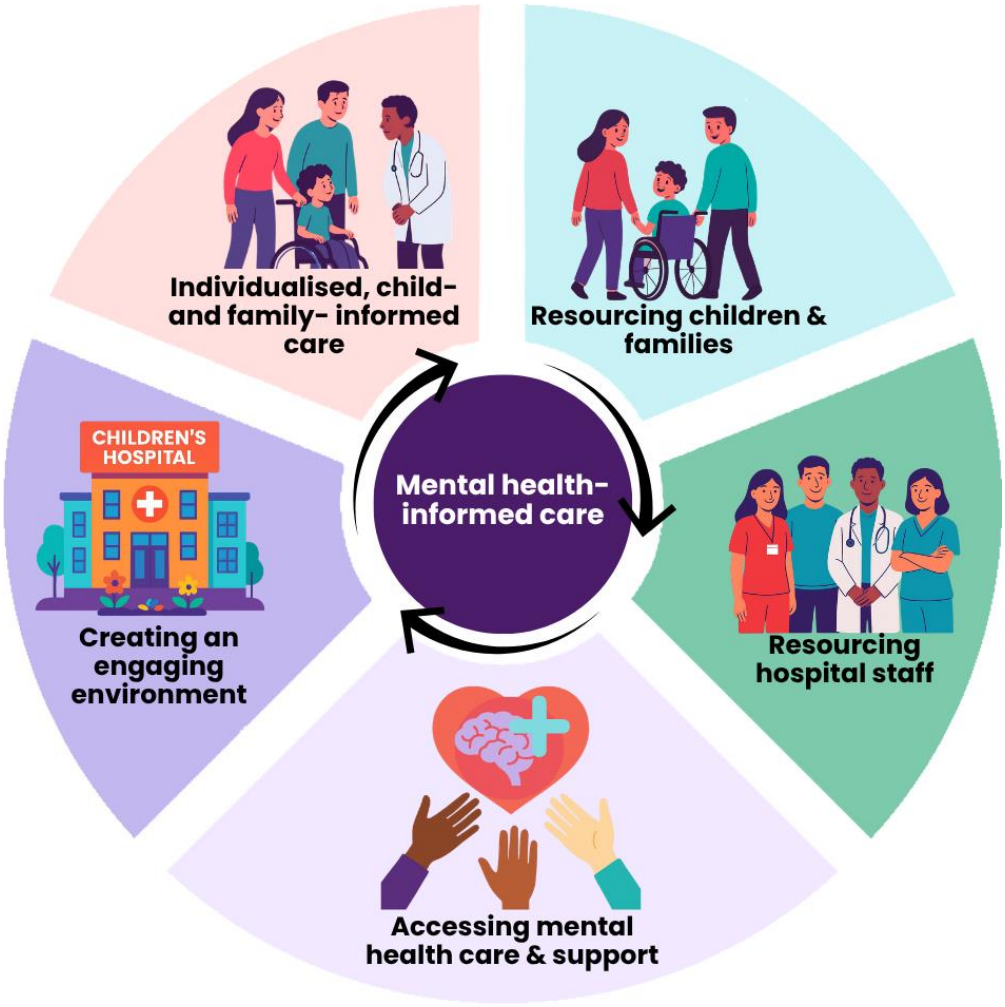


Figure 2. *Our framework of mental health-informed care. The figure shows five interacting priority areas that are centred around care that is mental health-informed. Mental health-informed care involves individualised care, practical and accessible mental health resources for children, family and clinicians, easy-to-navigate access to mental health supports, and attention to the physical environment. The central arrows indicate the interaction between these five elements. Strengthening any one of the elements will lead to improved mental health and wellbeing protection and support for children and young people with disability or chronic health conditions and their families.*

PRIORITY AREA 1: INDIVIDUALISED, CHILD- AND FAMILY-INFORMED CARE

The mental health and wellbeing of children and families must be supported through practices that are individualised and informed by the needs and preferences of the child and family. This helps children and their families to feel safe, informed, understood, and able to engage in their healthcare in ways that feel right for them, and to build the trust needed for this to happen.

PRIORITY AREA 2: RESOURCING CHILDREN & FAMILIES

Children and young people and their families need access to information and support that will promote their mental health and wellbeing. Being in hospital reminds children and young people that they are unwell or different. There are opportunities to make hospital visits easier and less stressful for them and their families.

PRIORITY AREA 3: RESOURCING HOSPITAL STAFF

Hospital staff need access to information, training, and support that will strengthen their knowledge, skills and confidence to support both the physical and mental health care needs of children and young people. Hospital staff need to feel confident and well equipped to explore and support child and family mental health and wellbeing. Staff wellbeing should also be prioritised as clinicians are more able to provide emotionally attuned, high-quality healthcare that supports child and family mental health and wellbeing when they too are well supported.

PRIORITY AREA 4: ACCESSING MENTAL HEALTH CARE & SUPPORT

A coordinated, easy- to-navigate system is needed to help children and families find and access appropriate mental health care, within and outside the hospital. It can be hard for children and families to find mental health care that is right for them. Clinicians also experience challenges connecting children and families with suitable mental health support when a need has been identified. Improving access to timely, ongoing and appropriate mental health care helps children and families feel safe, supported, and empowered.

PRIORITY AREA 5: CREATING AN ENGAGING ENVIRONMENT

Engaging, calming, and age-appropriate spaces are needed within the hospital to better support the wellbeing of children and families. The hospital can be an overwhelming and stressful environment for many children and young people. Providing physical spaces that promote comfort, play, relaxation, privacy and positive distraction can help children and families feel safer, more settled and better supported throughout their healthcare journey.

Recommendations – specific actions

The Mighty Minds LEAGs and study participants have developed a set of recommended actions within each priority area. These are presented in child- and family-centred language to reflect the perspectives of those involved. Please note that brackets at the end of each action indicate whether children and young people (CYP), parents/caregivers (P), and/or clinicians (CL) have proposed the action.

The mental health and wellbeing of children and families must be supported through practices that are individualised and informed by the needs and preferences of the child and family.

Recommended actions:

- Embed regular mental health and wellbeing check-ins at key stages and transition points (e.g., time of diagnosis, major surgeries or procedures, adolescence) to support early identification of mental health challenges (P, CL)
- Get to know me as a person, including my interests, identity, and family context – not only my disability or health condition (P, CYP)
- Understand my child's communication needs and preferences so that they can engage in their healthcare (P)
- Identify my child's sensory preferences to support their feelings of safety and comfort (P)
- Use strengths-based, supportive language that focuses on helping me manage my circumstances, rather than 'fixing' me (P, CYP)
- Be flexible and responsive to my/our needs in the moment (e.g., flexibility with appointment scheduling, understand that my needs might change) (P)
- Plan for difficult or sensitive conversations about my/my child's care to identify ways to minimise distress (e.g., who should/should not be present for those discussions) (CYP, P)
- When engaging with me/my child about my/their healthcare and/or mental health and wellbeing:
    - Behaviour is often communication. Observe and check in on your interpretation of my child's behaviour first, including their mood, energy, and self-regulation (P)
    - Interact directly with me while offering opportunities to 'opt out' of these discussions (CYP, P)
    - Allow adequate time and pacing so that I can process information (CYP, P)

- Consult and listen carefully to my parents and carers and in a way that's safe for me (P), recognising that they know me best (CYP)
- Know and understand my child's medical story (P) to support continuity and trust in your care (e.g., shared team handover time, reading my history on the medical record) (P)

Children and young people and their families need access to information and support that will promote their mental health and wellbeing.

Recommended actions:

- Provide accessible, developmentally appropriate information about what will happen before, during, and after appointments and procedures to reduce uncertainty and anxiety.
    - For example, appointment letters with visuals, visual schedules, RCH TV: Be Positive information videos for a range of ages and developmental stages (CYP, P)
- Offer activities that help to normalise the hospital experience, allowing me to engage in some of the everyday things that I enjoy even when I am at the hospital.
    - For example, group play sessions, pet therapy, arts and crafts, 'games box' (CYP, P, CL)
- Improve awareness and visibility of existing programs/supports (e.g., Starlight, Child Life Therapy, Disability Liaison Officer, RCH TV Be Positive videos), ensuring children and families know what is available and how to access it.
    - For example, a QR code for children and families that lists resources in the hospital that can be accessed to ease the burden of their admission/visit, posters around the hospital, brief 'orientation' for families during inpatient stays (CYP, P)

Hospital staff need access to information, training, and support that will strengthen their knowledge, skills and confidence to support both the physical and mental health care needs of children and young people.

Recommended actions:

- Use accessible visual tools, including colourful scales with pictures, to support communication about emotions, coping and wellbeing for children of all ages and developmental stages (P, CYP, CL)
    - For example, The Children's Wellbeing Continuum developed by the Centre for Community Child Health - https://www.ccch.org.au/our-work/project/childrens-wellbeing-continuum/

- Prioritise ongoing individual and team-based learning opportunities including:
    - Access to training that was reported as beneficial such as: Mental Health First Aid, Having Difficult Conversations, De-escalation (CL)
    - Development of/access to training identified as needed such as:
        - Mental health in physical and intellectual disability and chronic health condition modules (CL)
        - Understanding intellectual disability (P)
        - Supporting non-verbal patients and those with complex needs (P)
        - Understanding behaviour in the context of environmental factors, emotional states, and child factors and disability (P)
        - How to ask and respond about child and family coping and mental health and wellbeing (P)
        - How to practice within a strengths-based and trauma informed paradigm (P)
- Increase access to mental health support for staff within teams and hospital wards, ensuring clinicians have timely avenues for debriefing, emotional support and reflective supervision (CL)

A coordinated, easy-to-navigate system is needed to help children and families find and access appropriate mental health care, within and outside the hospital.

Recommended actions:

- Develop a central directory or interactive navigation hub for families and clinicians outlining available mental health supports, services and pathways, so mental health support options can be easily identified (P, CL)
- Routine check-ins by clinical staff with parents/caregivers about parent coping, family needs and support (P, CL)
- Expand the existing Family Hub to provide additional support and information that specifically addresses the mental health and wellbeing of families such as:
    - Information, resources, peer support opportunities for children and young people, (CYP, P)
    - Information, resources, support, peer support options and dedicated spaces for siblings (P)
    - Access to Family Therapy service within the hospital, particularly at the time of diagnosis and key transitions (P)
    - Lived experience liaison and specific peer support groups, e.g., for families navigating declining function, diabetes, intellectual disability (P, CL)

    - Parent peer led program(s) that builds parent capacity in advocacy, family relationships, and promoting and supporting their child's mental health through to adulthood (P)
- Ensure families have access to a mental health support phone number in every room to facilitate timely help-seeking (P)
- Embed care coordinator roles within teams to support navigation, continuity, and communication across services (P, CL)
- Strengthen partnerships between the hospital and community mental health providers to build shared mental health workforce capacity for children with disability and chronic health conditions (CL)
- Expand specialised mental health services for children with disability and chronic health conditions in the hospital (CL)

Engaging, calming and age-appropriate spaces are needed within the hospital to better support the wellbeing of children and families.

Recommended actions:

- Ensure that children have access to purpose-designed, inclusive and calming sensory spaces in waiting areas and across the hospital.
    - For example, quiet space, dimmed lights, comforting/sensory tools (CYP, P)
- Provide practical support to help families manage lengthy waiting times, during both outpatient appointments and inpatient stays.
    - For example, volunteers, SMS alert system for appointments about expected delays, changes, and wait times (CYP, P)
- Increase access to engaging, developmentally appropriate activities that also appeal to adolescents.
    - For example, toys (portable 'games boxes', arts and crafts, small mobile libraries) to support distraction, comfort and positive engagement while waiting for appointments and during hospital stays (CYP, P)

This research summary was developed by the Mighty Minds Investigator Team and Parent/Caregiver Lived Experience Advisory Group. The Young People and Parent Lived Experience Advisory Groups have made crucial and impactful contributions at every stage of the research since the study design and were integral to the outcomes of the study. Members of the Parent LEAG were Anna Commons, Sarah Botting, Ferdi Hepworth, Karen Jones, Ravneet Kaur, Daniela Kolev, Kirrilly Kratsis, Sophia Lee, Georgie Osborne, Juliette Permezel, Maya Pinn, Heather Renton, and Jessica Symes.

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