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National Workforce Centre for Child Mental Health

Supporting children's participation through shared decision-making in child mental health care

Michele Hervatin

This paper is part of a suite of resources focusing on children's participation in decisions that affect them. See all resources

What is this resource about?

This resource introduces practitioners to the concepts of children's participation and shared decision making in children's mental health care.[1] It discusses the benefits of involving children in decisions related to their own mental health care, as well as the challenges that practitioners may face when doing so. It also considers the ways that practitioners can support children's participation in decision-making processes related to their mental health care.

Who is this resource for?

This resource is for practitioners who provide services to children and their families in a mental health context, including allied health professionals (e.g. psychologists, social workers, occupational therapists). It can also be used by organisations that provide pediatric mental health care.

Key messages

- Shared decision making is the process of practitioners and patients working collaboratively to reach care and treatment decisions.

- Children's participation in decisions about their mental health care is a fundamental right.
- Shared decision making fits within the broader continuum of child participation and is a commonly researched method of participation in child mental health care.
- Emerging evidence suggests potential benefits of children's participation in their own mental health care, including in shared decision making. These advantages include:
  - upholding children's rights
  - utilising the unique and valuable perspectives of children
  - improving children's skills and traits; and
  - enhancing treatment outcomes.
- Practitioners can face challenges to involving children in decision-making processes related to their mental health care. These can include:
  - balancing participation with the need for safeguarding
  - considering concerns about children's capacity for involvement; and
  - balancing the perspectives of all involved (i.e. practitioner; child and parents; teachers and other professionals).
- Practitioners can support children's involvement in decisions related to their own mental health care, through personal characteristics, behaviours, tools and approaches.
- Further research is needed to identify the most effective tools and approaches for facilitating children's participation in their own mental health care, including shared decision making.

[1] This resource utilises child participation research for children aged 0–18 years. This is due to: 1) a lack of research specific to children aged 0–12 years; and 2) most research combining this age range with older participants.

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Introduction

There has been growing commitment internationally to children's meaningful participation in decisions about their health, including mental health care (Bjønness, Viksveen, Johannessen, & Storm, 2020; Cheng et al., 2017; Day, 2008; Edbrooke-Childs et al., 2016; Macdonald et al., 2007; White, 2020). This movement has also been seen in Australia in legislation, policy and initiatives supporting children's involvement in mental health care decisions (Macdonald et al., 2007).[2]

Practitioners and service providers in the child mental health sector increasingly aim to involve children, including in shared decision making, when delivering supports (Edbrooke-Childs et al., 2016; Simmons, Rice, Hetrick, Bailey, & Parker, 2015; The Royal Children's Hospital Melbourne, 2019; Young Minds, 2019).[3]

Definitions

For the purposes of this resource:

Child participation refers to the meaningful (i.e. active, safe, and informed) involvement of children in decisions that affect their lives. In the context of this paper, **child participation** often refers to children's involvement in, and influence over, their own mental health care (Day, 2008). It can also refer to children's involvement in decision-making processes about child and adolescent mental health services at an organisational level, such as those related to service planning, design, delivery, and evaluation (Day, 2008).

This resource focuses on including children in decisions about their own mental health care. A commonly researched form of child participation in children's mental health care is **shared decision making**. In this paper, the terms **child participation** and **shared decision making** will be used interchangeably.

What is shared decision making in child mental health care?

Shared decision making refers to the process of practitioners and patients working collaboratively to reach care and treatment decisions (Bjønness et al., 2020; Cheng et al., 2017; Liverpool, Pereira, Hayes, Wolpert, & Edbrooke-Childs, 2020). It can be viewed as having three main steps (Da Silva, 2012; Simmons et al., 2015; Smart, 2017):

1. The practitioner and patient exchange information in both directions.
2. The practitioner and patient discuss and consider the choices and preferences.
3. An option is chosen that aligns with the patient's preference and values.

Shared decision making may focus on decisions about administration of medication, lifestyle changes and participation in testing, or therapy or other interventions (Cheng et al., 2017).

Within children's mental health care, shared decision making has been relatively more researched compared to other forms of child participation. Internationally and in Australia, there has also been a growing emphasis on shared decision making with children and caregivers in child and youth mental health (Bjønness et al., 2020; Cheng et al., 2017; Edbrooke-Childs et al., 2016; Smart, 2017).[4]

The degree to which shared decision making can be practised in child mental health settings will be influenced by various factors, such as the setting (e.g. inpatient versus community) and the nature and severity of the mental health presentation (Gabe, Olumide, & Bury, 2004; Slade, 2017; Smart, 2017).

Importantly, shared decision making is often viewed as being located on the broader continuum of child participation activities, between approaches that are entirely practitioner-led versus those that are entirely patient-led (Cheng et al., 2017; Day, 2008, Slade, 2017; Smart, 2017). That is, shared decision making can be viewed as a form of children's participation (Cheng et al., 2017; Day, 2008).

Benefits of involving children in decision-making processes about their mental health care

Research on the benefits of children's involvement in their own mental health care, including in decision-making processes, is still emerging. Nevertheless, potential advantages have been identified in the literature (Macdonald et al., 2007; Mitchell-Lowe & Egglestone, 2009).[5] These include:

- upholding children's rights and their desire to be involved
- including the unique and valuable perspectives that children offer

[2] Examples include the *Mental Health Act 2014 (Vic.)* and the *National Youth Participation Strategy Project* of the Australian Infant, Child, Adolescent, and Family Mental Health Association.

[3] Examples include the *Mental Health Service* of The Royal Children's Hospital Melbourne, Orygen The National Centre of Excellence in Youth Mental Health, the Amplified Program of the National Health Service England, and various Child and Adolescent Mental Health Services in the United Kingdom.

[4] Examples include the *Mental Health Service* of The Royal Children's Hospital Melbourne and various child and adolescent mental health services (CAMHS) in the United Kingdom.

[5] This resource focuses on the potential benefits of children's involvement in processes and decisions related to their own mental health care. For a discussion of the broader benefits of children's participation more generally, refer to *An overview of child participation: Key issues for organisations and practitioners.*

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- fostering children's skills, empowerment and self-esteem
- enhancing treatment outcomes for children.

Upholding children's rights and their desire to be involved

Children's participation in their mental health care is a fundamental right. This right is enshrined in the United Nations (UN) Convention on the Rights of the Child (1989), which Australia has ratified (Australian Human Rights Commission, 2019; Goldhagen et al., 2020; Macdonald et al., 2007; White, 2020). Practitioners can help achieve Australia's responsibilities regarding children's rights through promoting children's participatory activities (Day, 2008).

Research, including that which explores children's own voices and perspectives, has generally suggested that children want to be included in decisions about their own health care (Abrines-Jaume et al., 2016; Coyne, 2006; Edbrooke-Childs et al., 2016; Kelsey, Abelson-Mitchell, & Skirton, 2007). While there is limited research exploring children's views on shared decision making specifically in child and adolescent mental health services (CAMHS), a review of research on children and young people's voices regarding CAMHS suggested that they want to be included in decisions that affect them (Dogra, 2005). Hence, practitioners should not assume that children do not want to be included (Advocate for Children & Young People NSW [NSW ACYP], 2019).

Preliminary research has also suggested that shared decision making is viewed positively by children (Cheng et al., 2017). Despite these findings, children may not always wish to participate (Day, 2008) and their choices should be respected. Involvement must be voluntary (Harris & Manatakis, 2013).

Including the unique and valuable perspectives that children offer

Children accessing mental health care have different needs and perspectives compared to adults (James, 2007; Mitchell-Lowe & Eggleston, 2009; NSW ACYP, 2019). For example, concerns about confidentiality and stigma may be more distinct in older children and young people at times of developing independence (Bjønness et al., 2020; James, 2007; Mitchell-Lowe & Eggleston, 2009). Children and parents can also have different, and even competing, views and priorities regarding treatment goals (Edbrooke-Childs et al., 2016; Macdonald et al., 2007). The voices of parents and caregivers cannot fully capture children's needs and views (Mitchell-Lowe & Eggleston, 2009).

Through consulting with children, practitioners can access unique views and feedback, including children's priorities and concerns (Day, 2008). This information can be used by practitioners to improve engagement, enhance knowledge, shape decision making, and inform treatment (Day, 2008; James, 2008).

Fostering children's skills, empowerment and self-esteem

Through supporting children to be involved in processes and decisions about their mental health care, practitioners can foster children's empowerment (Cheng et al., 2017; Day, 2008; O'Kane, 2013). This has been reflected in qualitative research exploring the voices of children and young people, which has suggested that involvement in decision making can lead to feelings of empowerment (Hayes, Edbrooke-Childs, Town, Wolpert, & Midgley, 2019). Shared decision making approaches have also been shown to lead to improvements in specific skills and traits, including self-efficacy, self-esteem, and communication skills (Abrines-Jaume et al., 2016; Bjønness et al., 2020; Day, 2008; Sinclair & Franklin, 2000). There is also the potential for growth in self-care skills (Day, 2008).

Enhancing treatment outcomes for children

Research on outcomes of shared decision making in child mental health is still emerging but there is early evidence for positive effects on treatment outcomes for children (Cheng et al., 2017). For example, shared decision making has been associated with improvements in child-reported levels of depression and quality of life, as well as reductions in parent-reported child mental health symptoms (Edbrooke-Childs et al., 2016).

Research conducted in the UK with child and adolescent mental health services has also found improvements in psychosocial difficulties (both child- and parent-reported) (Edbrooke-Childs et al., 2016); importantly, these child-reported improvements were only observed when both children and parents had reported higher levels of shared decision making. This highlights the importance of practitioners engaging in shared decision making with both children and parents to optimise outcomes (Edbrooke-Childs et al., 2016).

Shared decision making has also been associated with higher levels of child- and parent-reported satisfaction with mental health care (Cheng et al., 2017; Edbrook-Childs et al., 2016), which has relevance to practitioners who wish to optimise client satisfaction.

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Challenges to involving children in decision-making processes related to their mental health care

Practitioners may encounter challenges when involving children in decision-making processes about their mental health care. These can include:[6]

- the need for safeguarding and risk management
- concerns about children's capacity to be involved
- the difficulty of balancing multiple perspectives.

The need for safeguarding and risk management

Practitioners who deliver services in a child mental health context can face the challenging – but essential – task of balancing children's participatory activities with necessities of safeguarding, risk management and duty of care (Abrines-Jaume et al., 2016). Any activities must adopt a child-centred approach wherein a child's safety, protection, welfare and wellbeing are paramount (Department of Communities and Justice, 2019; Goldhagen et al., 2020).[7] In this context the prospect of implementing shared decision making may lead some practitioners to feel uneasy, hesitant and cautious due to concerns about safeguarding and risk (Cheng et al., 2017; Edbrooke-Childs et al., 2017).

Including children in decision-making processes in a child mental health setting can involve emotion-charged, complex conversations (Edbrooke-Childs et al., 2017; Wolpert et al., 2012). This may generate concerns about the potential impact of such activities on children, who are often vulnerable and experiencing high emotional difficulties (Abrines-Jaume et al., 2016; Edbrooke-Childs et al., 2017; Wolpert et al., 2012). As a result, some practitioners may consider participatory activities as a potential burden or therapeutic risk (Abrines-Jaume et al., 2016).

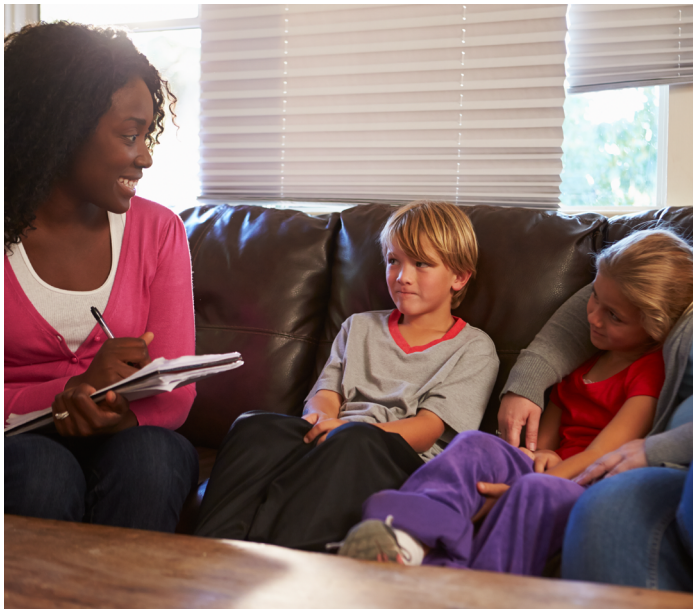
Concerns about children's capacity to be involved

Some practitioners have raised concerns about whether children have the skills and capacity to participate in decision-making processes related to their mental health care (Cheng et al., 2017; Day, 2008; Edbrooke-Childs et al., 2017; Gondek et al., 2017; Phillips & Coppock, 2014). For example, questions have been posed about the extent to which a child's age and/or level of development (e.g. cognitive, emotional) might affect their:

- level of knowledge
- capacity to offer information that is accurate and unbiased (e.g. historical information, self-reports about psychological states and symptoms)
- capacity to form collaborative goals for treatment (Cheng et al., 2017; Day, 2008).

These capacity concerns are echoed in the wider literature on children's participation (Cheng et al., 2017; Day, 2008; Edbrooke-Childs et al., 2017; Gondek et al., 2017; Phillips & Coppock, 2014). However, broader research on child participation that is sensitive to these developmental issues has suggested that children can reflect on their experiences and can make complex contributions to decision making (Day, 2008).

Nevertheless, additional research is needed to specifically investigate the capacity of children with mental disorders to contribute to their mental health care processes and decisions (Simmons et al., 2015). For practitioners in mental health settings, capacity considerations might be intensified by concerns that mental health problems could potentially affect children's participation in decision making (Cheng et al., 2017; Day, 2008).



6 This list of challenges is not exhaustive. These challenges occur against a background of more generalised barriers to children's participation. For a discussion of the broader challenges to child participation, refer to *An overview of child participation: Key issues for organisations and practitioners.*

7 The importance of a child-centred approach is ingrained in section 9 of the Children and Young Persons (Care and Protection) Act 1998. The Act states that actions and decisions about a child must hold their safety, protection, wellbeing, and welfare as paramount (Department of Communities and Justice, 2019). The *National Principles for Child Safe Organisations* provide a national approach to embedding child safe cultures.

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The difficulty of balancing multiple perspectives

Children who receive mental health services are generally seen in the context of their family (Macdonald et al., 2007). In some circumstances, children may not receive treatment themselves, with this instead provided to parents or caregivers (Liverpool et al., 2020; Macdonald et al., 2007). Consequently, the practitioner is often required to consider multiple service users (Edbrooke-Childs et al., 2016; Macdonald et al., 2007). These parties may have competing perspectives, needs and priorities (Edbrooke-Childs et al., 2016; Macdonald et al., 2007). Practitioners must involve both children and parents when understanding treatment goals, communicating information about choices and preferences, and forming a shared action plan (Edbrook-Childs et al., 2016). The views and goals of education providers and other professionals may also require consideration (Abrines-Jaume et al., 2016).

The broader child–parent–practitioner triad can also present a challenge for practitioners implementing shared decision-making approaches. These parties can differ on various issues (Day, 2008; Edbrooke-Childs et al., 2016; Gondek et al., 2017; Hawley & Weisz, 2003; Liverpool et al., 2020; Yeh & Weisz, 2001), such as:

- the reason for the referral
- the presenting problem/s
- the nature and severity of the mental health concerns
- the goals of treatment.

Multiple perspectives must be carefully considered, compared and balanced but this can be difficult if there is conflict about goals, priorities, needs or actions (Macdonald et al., 2007).

Supporting children's participation in decision-making processes

Practitioners can support children's participation in decisions related to their mental health care in various ways. Examples include:[8]

- demonstrating patience, effort and characteristics of helping
- demonstrating and building trust
- being flexible and adaptive
- using tools and approaches.

[8] This resource specifically focuses on how practitioners can support children's participation in processes and decisions about their mental health care. The approaches discussed are not exhaustive. For an in-depth discussion of facilitators of children's participation more broadly, refer to *An overview of child participation: Key issues for organisations and practitioners.*

Demonstrating patience, effort and characteristics of helping

Through demonstrating core 'helping characteristics', practitioners can facilitate children's engagement and involvement in processes, planning and decisions related to their mental health care (Day, 2008, p. 4). These characteristics include warmth, caring, openness, respect, understanding and inclusiveness (Bjønness et al., 2020; Day, 2008; Harris & Manatakis, 2013).

Patience and being prepared to allocate additional time and effort are also likely requirements for promoting children's participation in processes and decisions related to their care. For example, extra time and effort may be needed to (Abrines-Jaume et al., 2016; Cheng et al., 2017):

- ensure information is understandable and accessible
- ensure children understand the options that are available
- allow children to reflect upon, form and communicate their views and preferences.

Demonstrating and building trust

Trust is a key facilitator of children's involvement in decisions about their mental health treatment (Abrines-Jaume et al., 2016; Bjønness et al., 2020; Cheng et al., 2017). For example, practitioners being prepared to place their trust in children to meaningfully participate in these decisions can enable shared decision making (Abrines-Jaume et al., 2017).

Trust between children, parents/caregivers and practitioners is also viewed as critical for children's inclusion in decision making (Cheng et al., 2017). Examples of practitioner strategies that might promote trust (Abrines-Jaume et al., 2017) include:

- considering whether it might be appropriate to allow the child to lead the session and so have some control
- coming to a mutual agreement about the timing, format or setting of appointments
- discussing who will be present for specific sessions.

Being flexible and adaptive

Children who access mental health services are diverse in age, developmental level, needs and presenting issues (Cheng et al., 2017). Consequently, practitioners must flexibly tailor their approaches to each child to ensure meaningful participation in decision-making processes (Bjønness et al., 2020; Cheng et al., 2017). For example, children with language difficulties may need specific strategies to ensure their understanding of information and to enable communication of their views and preferences; for some, non-verbal forms of

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communication may be helpful (e.g. communication boards, drawings, demonstrations) (Abrines-Jaume et al., 2016). For a deeper discussion of tailoring engagement approaches for specific groups of children, refer to *Practical strategies for engaging children in a practice setting.*

Practitioners may also need to adapt by altering their mindset of themselves as the sole expert. This may be unfamiliar for some given that clinical training often strives to produce 'expert professionals' (Abrines-Jaume et al., 2016, p. 27; Bjønness et al., 2020). This shift could involve sharing some control over therapy and decisions with children, who are often viewed as less knowledgeable about mental health and treatment (Abrines-Jaume et al., 2016).

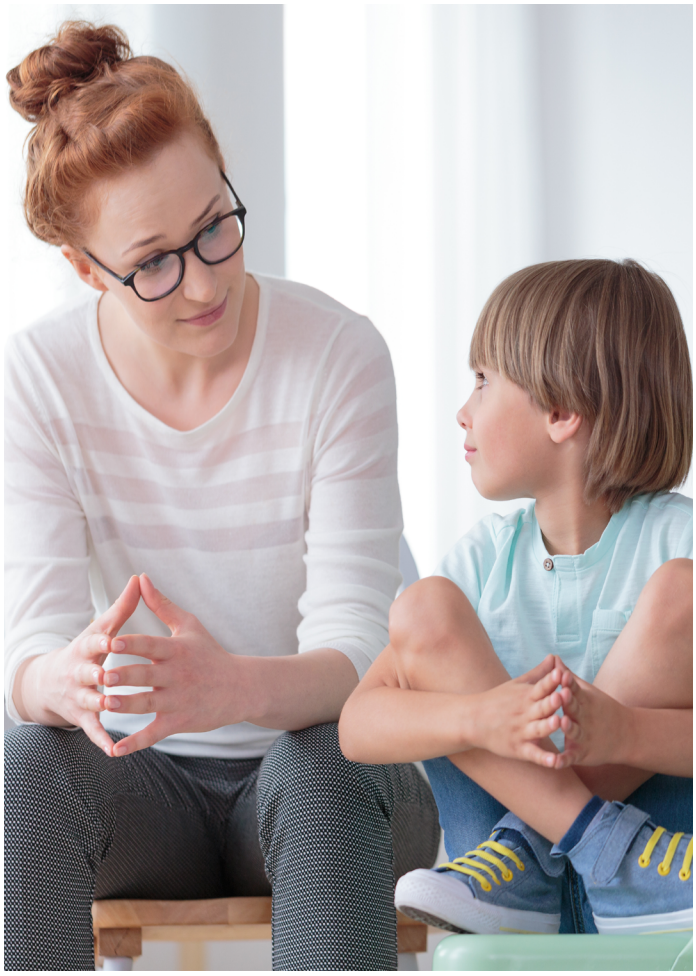
Importantly, shared decision making with children via the above approaches does not involve a practitioner giving total control to the child; rather, the aim is to combine the unique expertise of children and practitioners (Abrines-Jaume et al., 2016; White, 2020).

Using tools and approaches

Numerous tools and approaches exist that can be used to support shared decision making. However, it is important to note that many of these have not been trialled in a child mental health setting, are often created for adults, and can lack thorough evaluation (Cheng et al., 2017; Day, 2008).

Nevertheless, research has identified six main approaches that support shared decision making in child mental health (Cheng et al., 2017):[9]

- Providing children with psycho-educational information with the expectation that it might promote shared decision making.[10]
- Using **decision aids** (i.e. paper-based or online tools that help children to make decisions about their mental health care).
- Engaging in **goal setting** and **collaborative action planning** with children to inform treatment, and tracking goals over time.
- Using **discussion prompts** that support children in conversations about their care (e.g. question lists; cards with words or visuals).



- Using **mobilisation approaches** that aim to increase children's engagement in their mental health care and their motivation and readiness for decision making.
- Using **therapeutic techniques** designed to support shared decision making (e.g. a framework for facilitating collaborative decision making around medication).

High-quality evidence is still required to establish the effectiveness of these different approaches, including research that clarifies clinical outcomes and incorporates children's perspectives (Cheng et al., 2017). However, early research has suggested that regardless of the specific approach being used, the degree to which it can be adapted to the target population (i.e. its flexibility) is likely to be critical. Approaches that can be tailored by practitioners and children might offer greater benefits (e.g. goal-setting approaches, some decision aids) (Cheng et al., 2017).

Beyond the work of individual practitioners, organisational resources and support are critical to enabling practitioners to promote participatory activities and shared decision making. See below for an overview of how organisations can support practitioners.

[9] This scoping review identified six main approaches from 22 records. Eight of these records had approaches that targeted children or young people. Given this area is under-researched, however, this review has been highlighted. All approaches listed here targeted children or young people in at least one record.

[10] For example, an online resource titled My CAMHS Choices 'provided information to [children and] young people aged 10 to 18 years and their families about what to expect at CAMHS, with the explicit aim of promoting greater collaboration in decision-making' (Cheng et al., 2017, p. O1498; Evidence Based Practice Unit, 2014).

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How can organisations support children's participation in their own care?

When considering children's inclusion in decision-making processes related to their mental health care, it must be acknowledged that the practitioner exists within a larger organisation that can influence their ability to involve children in these processes (Cheng et al., 2017).[11] For example, many child and adolescent mental health practitioners and services are experiencing substantial pressures within a context of limited resources (Abrines-Jaume et al., 2016). Children's participation in shared decision making can be effortful and time-consuming.

Organisations can support practitioners who strive for children's participation in the delivery of mental health care in various ways (Abrines-Jaume et al., 2016; Day, 2008; Macdonald et al., 2007).

Supporting children's participation and its value

Organisations may wish to support children's participation through:

- promoting an environment that values and supports children's engagement in participatory activities (Department of Communities and Justice, 2019; Macdonald et al., 2007)
- providing positive feedback to practitioners who engage in these practices (Abrines-Jaume et al., 2016)
- developing organisational policies that address the participation of children and young people separately from parents and caregivers (Macdonald et al., 2007)
- creating an integrated framework for participation that supports the unique role of children and parents, while also taking into account developmental considerations (Macdonald et al., 2007).

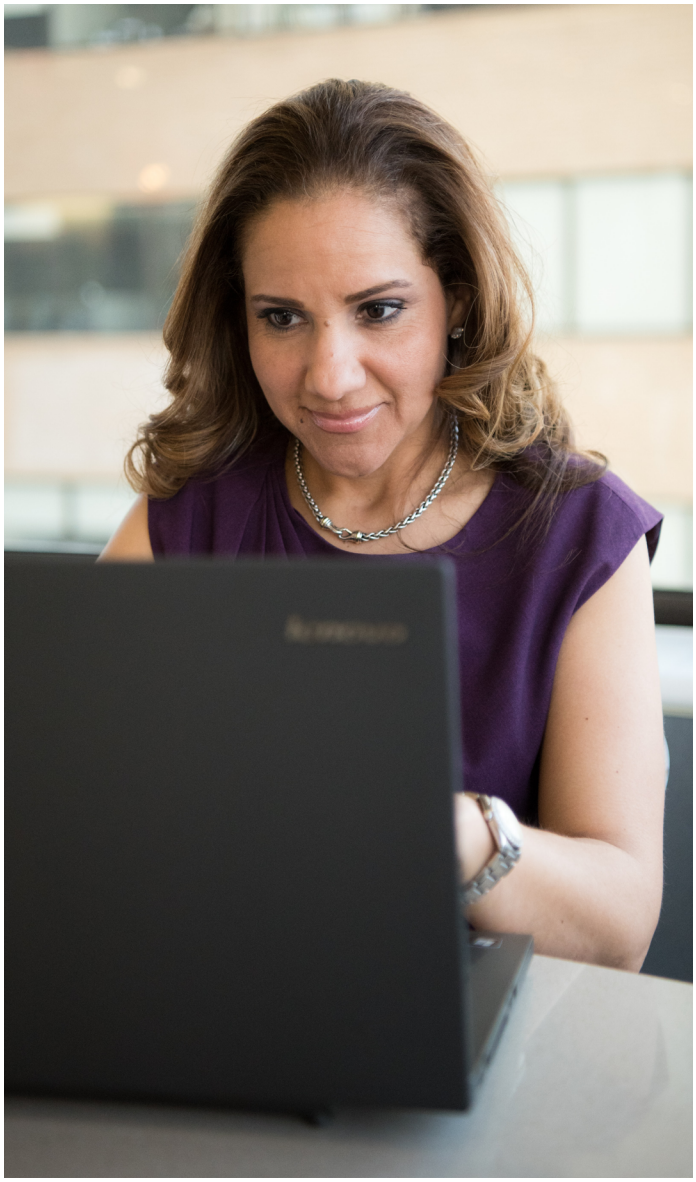
Encourage patient-centred care

Strong organisational support and encouragement of patient-centred care can facilitate participation (Gondek et al., 2017; Harding, Wait, & Scrutton, 2015). Patient-centred care is a system that supports service users to (Bjønness et al., 2020; Harding, Wait, & Scrutton, 2015):

- manage their own care and health in a successful manner
- make informed choices
- receive care that considers their individual views, abilities, lifestyles, preferences and goals.

Allocating additional resources where possible

Where circumstances allow, organisations should allocate additional supports to help practitioners to meaningfully involve children, including in terms of funding, training and allocation of time (Abrines-Jaume et al., 2016; Bjønness et al., 2020; Macdonald et al., 2007). It is important to acknowledge, however, that the extent to which organisations will be able to enact these processes is likely to be influenced by broader contextual factors (e.g. those at a systems-level or policy-level) (Cheng et al., 2017; Gondek et al., 2017).



[11] This section discusses some of the organisational facilitators in the child mental health literature on children's participation. However, these occur against a background of more generalised organisation-level facilitators of child participation. For an in-depth discussion of these broader facilitators, refer to *An overview of child participation: Key issues for organisations and practitioners.*

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- An overview of child participation: Key issues for organisations and practitioners (practice paper)
- Children's participation in decision-making processes in the child protection system (practice paper)
- Practical strategies for engaging children in a practice setting (practice paper)
- What is effective professional practice from the perspective of children and young people? (short article)
- Engaging with Children: A Foundation (e-learning course)
- Engaging children as partners in practice to support their mental health and wellbeing (webinar)

Further reading

- Anna Freud National Centre for Children and Families. (2019). Shared decision making. Available here.

This website provides an introduction to shared decision making in child and adolescent mental health services, and discusses why it is important. It offers resources and tips for mental health professionals for engaging young people in shared decision making.

- Day, C. (2008). Children's and young people's involvement and participation in mental health care. Child and Adolescent Mental Health, 13, 2–8. doi: 10.1111/j.1475-3588.2007.00462.x

This journal article provides an introduction to children and young people's participation in their own mental health care, including benefits and challenges. It also discusses involving children and young people in the planning, design and delivery of child and adolescent mental health services.

- Department of Communities and Justice. New South Wales Government. (2019). Engaging children, young people and families. Available here.

This website provides an introduction to engaging children, young people and families, including their involvement in decision-making processes. Practice points are offered.

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