



# Evolving by Involving

Involving young people and their parent/carers  
in mental health care

**YOUNG**MiNDS   
Transforming participation across young people's mental health

# About Amplified

This toolkit was created as part of the Amplified project. Run by YoungMinds and commissioned by NHS England, Amplified is a programme that aims to support the participation of children, young people and their families at every level of the mental health system. We support providers and commissioners to excel in participation by showcasing good practice across the system and promoting access to resources that support in four areas:

- Promoting and championing participation
- Strategic participation of children, young people and their families
- Promoting young people's access to and their voice within services
- Supporting the collaboration of young people and their families in care and treatment

## Amplified advisors

The Amplified programme has a group of youth and parent and carer advisors that are closely involved in many aspects of our work. Amplified Advisors make sure that the voices and needs of young people and parents are at the heart of everything Amplified offers.

## Jargon buster

Jargon and acronyms used in this publication are laid out below:

CAMHS – Child and Adolescent Mental Health Services

CYP – Children and Young People

For a more thorough glossary of mental health acronyms visit [youngminds.org.uk/media/3409/speaking-the-same-language-on-mental-health.pdf](https://youngminds.org.uk/media/3409/speaking-the-same-language-on-mental-health.pdf)

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# Introduction

**“Shared-decision making pools the expertise of the therapist and the service user and leads to better, more effective interventions than professional judgement alone.”** - Abrines-Jaume, N et al (2013)<sup>1</sup>.

Including young people and their parents/carers in decisions about their care is key to establishing and maintaining trust, creating a healthy working relationship, and achieving the best outcomes.

This resource aims to help professionals consider the best ways to ensure you and your service are creating opportunities for genuine involvement at every level of care. It provides advice and experience from young people and parents and carers who have received mental health support, and looks at potential barriers professionals may face.

## My story

*“When I first attended CAMHS at 13 years old, I remember feeling anxious. I didn’t want to be there...*

*This changed when my local CAMHS created a children and young person’s focus group. Initially I felt extremely nervous at the thought of taking part but, after encouragement from my doctor, I signed up. I am so glad I did - this has been one of the best decisions I have made.*

*I had other opportunities to develop new skills, like when my local NHS trust provided me with interview skills training. Myself, the participation worker and some of the friends I made at the focus group travelled together to the training course. We had pizza, learnt new communication skills and took part in team building-exercises, which built our confidence. Soon after, I was on an interview panel with a doctor and psychologist - asking some questions, working together and deciding who should get the job! I never imagined that I would be able to do anything like that.*

*During my transition from CAMHS to adult mental health services, I worked alongside my team to create a new care plan that worked for me. I spent time with the team so they could get to know me as a person and we could talk about the things I valued, which helped us come up with goals that worked for me and what I wanted to achieve. Over time I became better equipped to make decisions about my own treatment and to discuss the risks and benefits of different treatment options. It was on this foundation that I built a trusting relationship with my team, where I not only felt listened to but understood.”*

Extract from a blog by Josephine, Amplified Youth Advisor. An extended version of Josephine’s blog can be accessed at the end of this resource.

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<sup>1</sup> Abrines-Jaume, N., Midgley, N., Hopkins, K., Hoffman, J., Martin, K., Law, D., & Wolpert, M. (2016). A qualitative analysis of implementing shared decision making in Child and Adolescent Mental Health Services in the United Kingdom: Stages and facilitators. *Clinical child psychology and psychiatry*, 21(1), 19-31. [doi.org/10.1177/1359104514547596](https://doi.org/10.1177/1359104514547596)

# What do we mean by ‘involvement in care’?

“For many young people it is often harder to engage with a service if you feel as though treatment and support is being done to you rather than with you”

- Amplified Youth Advisor

Future in Mind, the report of the Children and Young People’s Mental Health Taskforce, emphasises that treatments should be offered in ways that young people and their families find acceptable, accessible and useful. It states that “...the best mental health care and support must involve children, young people and those who care for them in making choices about what they regard as key priorities, so that evidence-based treatments are provided that meet their goals and address their priorities.”<sup>2</sup>

Involvement in care is the idea of allowing young people and their parents/carers to collaborate when making decisions and allowing young people to be actively involved in the care they are receiving from a service or professional. This is also known as individual participation.

**Individual participation: young people’s involvement in decisions and actions related to their own mental health, including in decisions related to care and treatment they receive.** - YoungMinds

Genuinely involving young people and families in decisions about support is a key way of building trust. Including young people in their care allows a sense of autonomy in a setting and situation that can sometimes feel daunting and scary.

There are lots of different words used to describe this type of participation in care - the following are some of the most common .

**Shared decision making:** ‘The process by which a young person and their healthcare professional reach a decision together about treatment options and next steps. It requires young people and professionals to understand what is important to each other when choosing a treatment, weighing up clinical evidence and preferences.’ (NHS England<sup>3</sup>).

**Patient Involvement:** ‘Individuals being involved and owning decisions about their own care’ (Department of Health and Social Care<sup>4</sup>)

**Self-management:** ‘Approaches that aim to enable people living with long term conditions to manage their own health effectively’ (NHS England<sup>5</sup>)

<sup>2</sup> Department of Health & NHS England (2015) Future in Mind: Promoting, protecting and improving our children and young people’s mental health and wellbeing.

[assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414024/Childrens\\_Mental\\_Health.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf)

<sup>3</sup> NHS England (2017) Involving people in their own health and care: Statutory guidance for clinical commissioning groups and NHS England [england.nhs.uk/wp-content/uploads/2017/04/ppp-involving-people-health-care-guidance.pdf](https://england.nhs.uk/wp-content/uploads/2017/04/ppp-involving-people-health-care-guidance.pdf)

<sup>4</sup> Department of Health and Social Care (2011) Patient Involvement and Public Accountability: A report from the NHS Future Forum [assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213752/dh\\_127544.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213752/dh_127544.pdf)

<sup>5</sup> NHS England (2017) Involving people in their own health and care: statutory guidance for clinical commissioning groups and NHS England [england.nhs.uk/wp-content/uploads/2017/04/ppp-involving-people-health-and-care-plain-text.docx](https://england.nhs.uk/wp-content/uploads/2017/04/ppp-involving-people-health-and-care-plain-text.docx)

# Top tips for involvement in care

We asked our Amplified Youth and Parent/Carer Advisors what involvement in care means to them. Below are their responses and advice for professionals on how best to involve young people and their carers in making decisions about their mental health support.

1. One size does not fit all. Young people are individuals and have different needs. Tailor information to a specific young person. Some people will want lots of information, discussion and time to process, others may only be able to choose between two basic options.
2. Engage with parents/carers - treat them as your equal in recognising the knowledge they bring to the table. They have known their child/young person forever, you have known them for a few moments.
3. If your approach isn't working then change it! Ask the young person or parent/carer what they think will work.
4. Successful outcomes are more likely to be achieved if young people 'own' the intervention and feel their voices/opinions on their own care matter.
5. Maintain a person-centred approach - no young person or parent/carer is the same. A 'prescriptive' 6 week series of 'worksheets' can feel like a tick box exercise. Just because they have finished it by no means indicates that they feel it is helping or that it is appropriate to their needs.
6. Things that might seem small or insignificant to you might mean a lot to a young person, sometimes being involved in making decisions on 'smaller' things e.g. where to sit in a treatment room can help a young person to feel like they are in control of their care.
7. Allow a young person choice in the involvement of parents/carers - how much they can know, what they don't want them to know/be involved in etc.
8. Make the experience of receiving support a safe one, explaining exactly what happens when, and that there isn't a right or wrong answer or choice to make.

**“By better understanding the wants, needs and views of the young person and their parent/carer, the professional is in a better place to understand how best to support them and their family.”**

- Parent/Carer Advisor, Amplified

# Why is it important?

## Why is it so important for young people and parents to be involved and make decisions within their care?

Young people need, and deserve, to feel like they understand and are involved in the treatment that they are receiving. Together practitioners and young people should review the possible treatment options and both the parent/carer and young person should play an active role in making a decision about the care given. Young people and their parent/carers should be kept up to date and involved on an ongoing basis. Successful participation and shared decision making allows them to be part of the solution.

Involvement in care is highly researched and discussed. Whilst it may initially seem like extra work for a practitioner, ensuring that shared decision making is part of your work can have many benefits for all involved.

We asked parents, young people and professionals why they thought it was so important:

**“It improves outcomes for young people if they feel they are involved and have choice and autonomy about what treatment they have. Particularly in mental healthcare, there are many people who’ve seen multiple professionals already and letting them tell you what worked/didn’t work, means moving forward we can do better for healthcare professionals and young people.”**

– Parent/Carer Advisor, Amplified

**“Participation in treatment is so important to so many young people. Imagine going into hospital for a broken leg, not knowing any of the usual treatments, when a doctor you don’t know comes in, in silence, and manipulates your leg to give you an X-ray and then puts a cast on. How do you feel? Confused? Scared? Hopeless? That’s how many young people feel when accessing mental health services for the first time.”**

– Lorna, Youth Advisor

**“It is vital that young people - that those who care for them - have the opportunity and right to have a say about issues and decisions that affect them. And within this shape their care and goals. It supports developing young people’s skills, wellbeing and enables a closer connection- therapeutic engagement. This ultimately improves the quality of care.”**

– Al Ford, Assistant Director, Manchester CAMHS

# Involving young people

Whilst involving young people in care can seem daunting to many professionals, there are many simple ways to ensure that you are supporting a young person to feel like they are in control of their treatment.

## How do young people want to be involved?

**“The first steps are so simple: How did you feel? Was there anything we could do to make things better? These efforts make such a difference to the lives of so many young people who are navigating the complicated world of mental health care.”** – Lorna, Amplified Youth Advisor

Things that might seem small, for young people, can make a real difference when it comes to accessing care. There are many ways to involve young people at all levels of care, from something as simple as where to sit in a room for an appointment, to the type of treatment they access.

For young people it is about having honest and open conversations about what is/isn't working, how they want to access treatment and the pros/cons of decisions.

## Why is this important to young people?

Our youth advisors share their experiences.

**“It gives people control of their own life when lots of things feel out of control”**

**“It can avoid some trauma where historically things are done ‘to us’ rather than with us”**

**“Open discussions support everyone to be on the same page of understanding so it makes professionals job easier too.”**

**“Being given a choice over when I had my appointment, it sounds silly, but it’s the only time I felt like I had any control”**



# Involving parents and carers

Not all young people feel able to participate within their care. This can be for various reasons but it doesn't mean that practitioners should make decisions alone. In some cases young people may want their parents to be involved in their care.

## Why involve parents?

Our parent and carer advisors share their views and experiences.

**“If my young person isn't able to verbalise the care they need, I as a parent can help.”**

**“Parents are ‘living’ their child's mental health difficulties alongside their child. The information they hold on their child as a result cannot be dismissed and will be key to finding a solution to their child's situation.”**

**“Parents/carers have a wealth of information about their child/young person and on this basis form part of any solution. Without listening to us and our young people you risk making huge assumptions about care needed. This is a costly mistake - both financially but more importantly to those you are aiming to support.”**

## Some tips from parents:

**“Do not call me mum/dad! I have a name - please afford me the same respect you would others around the table and please don't talk about me as if I'm invisible!”**

**“The more you work with parents, the more you will find out about the young person - this can only be beneficial.”**

# Potential barriers

For some young people there may be barriers to being involved within their care. These are wide ranging, and include various reasons.

## The 5 Barriers Framework

(Peter Figueroa, 1993)<sup>6</sup>

- Personal barriers relate to a young person's values, attitudes, personality, biological and genetic conditions
- Interpersonal barriers are concerned with the interactions between individual young people and the people they directly encounter e.g. teachers, GPs, pastoral staff, youth workers, community leaders etc.
- Structural barriers result out of policies, funding, media, and priorities in any of these; these barriers affect a person's status, power and relationships
- Institutional barriers are those that exist in larger, formalised networks that have rules and systems in place to manage access and shape attitudes (schools, health services, communities etc.)
- Cultural barriers are created by shared assumptions shaped through history, cultural identity, socialisation, social construction of gender stereotypes, hegemonic masculinity or white privileges

**Young people and parents/carers shared some examples that have stopped them being involved in their care:**

### Personal

- A lack of self-esteem
- The young person and parent/carer being in a potentially vulnerable place and feeling unable to approach the topic themselves
- Symptoms - like psychosis - making it more difficult (though not impossible with the right support)

### Interpersonal

- Not having good support systems in place
- Not believing that they'll be heard by the professional
- It can be difficult for a young person or their parent/carer to initiate the conversation around choice or decision making

### Structural

- Lack of prior experience of being given choices
- No knowledge that participation in care is possible

### Institutional

- Previous poor experiences where they were not listened to
- The young person being used to teachers or other professionals being 'in charge' in other everyday situations

### Cultural

- Culturally for some communities asking questions to professionals is not something that is done often

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<sup>6</sup> Fyfe, A & Figueroa, P (Eds) (1993) Education for Cultural Diversity: The Challenge for a New Era, London: Routledge

# Language, communications and accessibility

We often hear that young people and parents and carers can be unclear on their rights when it comes to confidentiality, making complaints and how much they can be involved in their care. We also hear that there is a lot of jargon and use of acronyms in mental health services that people don't understand.



YoungMinds previously created a mental health glossary which gives young people and parents and carers a run-down of the most common terms that people found confusing. We have also created posters which cover being involved in decisions about your care, how to give feedback and how your information can be shared.

If you are a professional in CAMHS, you could put the posters up somewhere in your service so everyone can feel more informed about their rights.

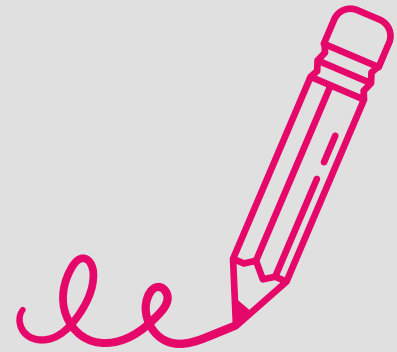
These resources can be accessed here: [youngminds.org.uk/youngminds-professionals/our-projects/amplified/amplified-resources/camhs-glossary-and-posters](https://youngminds.org.uk/youngminds-professionals/our-projects/amplified/amplified-resources/camhs-glossary-and-posters)

# Accompanying resources

See the links below to some extra resources made by our activists.

## Blog

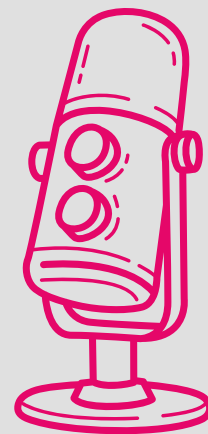
Amplified youth advisor, Josephine, shares her experience of participating in her own care and the empowerment that it gave her. She explains what she was able to be involved in, how this made her feel and how this aided her recovery.



[youngminds.org.uk/josephines-story](https://youngminds.org.uk/josephines-story)

## Podcast

Another of our youth advisors, Jess, talks to you about the importance of participation, and what she has gained from it as a young person. She shares her advice on what makes participation meaningful and how you, as a practitioner, can work with young people.



[youtube.com/watch?v=292V5MIJc3A](https://youtube.com/watch?v=292V5MIJc3A)



# Conclusion

We often talk about participation and what it looks like in terms of how services are designed and shaped. But arguably, the most important participation is that which starts with a young person being involved in decisions about their care.

Genuinely involving young people and parents and carers in decisions about their care can offer huge benefits, not just for the young person, but also for your organisation. Your service is providing support through one of the most difficult experiences of a young person's life, and it is crucial they are offered an opportunity to play an active role in shaping what that support looks like.

It can be difficult to consider how your organisation can sincerely and effectively share power and responsibility with young people and their families, but making it happen has the potential to create more positive engagement and better outcomes for young people.

One of the things that comes through clearly from our advisers in this resource is the power of listening. Listen to what young people and parents and carers are saying and try to work with them to achieve their ambitions. One size won't fit all and being adaptable, you can learn what works best for a young person and what will help them in their recovery. Dismissing the expertise of a young person or their parent or carer is detrimental to both the organisation and the individual. We benefit when we truly consider the ways that both the professional and a young person can work together in a safe environment to create effective support.

We hope that the feedback and advice included in this resource provides a starting point to ensure participation in care is recognised as a central part of a young person's recovery or management of their mental health.



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