

What is participation in children and young people's mental health?

Grounding

Building

Applying

What is participation?

Introducing participation

Simply, participation means individual's involvement in decisions that affect them.

NHS England guidance on participation sets out two types of participation in healthcare: 1) people's involvement in decisions about their own health – what it calls individual participation and 2) people's involvement in the design and delivery of health services they use- what it calls public participation.

Thinking about young people's mental health, we could describe these **two types** of participation as:

1. **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
2. **Public participation:** young people's involvement in shaping the design and delivery of interventions and services that promote and support their mental health, including in commissioning

NHS England policy in children and young people's mental health makes clear that both types of participation- individual and public- must be promoted and embedded across the children and young people's mental health system.

See the [Amplified Grounding Pack: Participation in Policy](#) for more information.

Involving young people in improving their services gives them more autonomy and the ability to make positive changes for both themselves and future service-users

Lorna
Amplified Youth Advisor

What is participation?

Children and young people's participation is one of the five key principles of the CYP IAPT programme. In 2011 YoungMinds held conversations with children and young people and professionals about participation in children and young people's mental health. The resulting report: **Talking about Talking Therapies** set out the **nine Participation Priorities** for the CYP-IAPT programme.

These priorities are:

Feeling Good...



Priority 1:

Get initial assessments right

Priority 2:

Make sure session monitoring involves the young person

Priority 3:

Provide easy access to complaints and advocacy

Doing the job right...



Priority 4:

Make sure staff have the right skills and knowledge

Priority 5:

Involve young people in recruitment

Priority 6:

Involve young people in staff appraisals

Running the service well...



Priority 7:

Involve young people in commissioning

Priority 8:

Help young people influence senior managers

Priority 9:

Have a strong mission statement

The Amplified training and development programme is based on these nine participation priorities.

What is participation?

Individual participation: Common Terms

There are lots of different words used to talk about participation in children and young people's mental health. This section sets out some of the most common. Different terms will be more common in different types of organisation and these terms are all used within the children and young people's mental health system.

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). See the next page for more on shared-decision making.

Patient Involvement: 'Individuals being involved and owning decisions about their own care' (Department of Health)

Self management: 'approaches that aim to enable people living with long term conditions to manage their own health effectively' (NHS England)

We never say "patient", we always use the term "young people/persons"

Head of CYP Health Improvement, Local Improvement

What is participation?

Shared-decision making is about supporting young people to play an informed role in sharing decisions about the mental health care they receive by: enabling young people to understand the care options available to them, the risk and benefits associated with each and how these align to their personal priorities and values.

‘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).

Research in shared-decision making in young people’s mental health sets out five stages:

1. Young people and those working with them agree key problems and goals together
2. Those working with young people support them to understand the options available to them
3. Young people and those working with them agree which options for help they will try
4. Young people and those working with them review progress
5. Young people and those working with them discuss options and make any changes as necessary (Wolpert, Dr M. Closing the Gap: Shared Decision Making in CAMHS)

Shared-decision making has been shown to make relationships between young people and the professionals supporting them to be much more open. It can also help young people feel more involved in their care and more committed to following their care plans. (Abrines-Jaume, N et al (2013).

What is participation?

Some resources that can help understand and practice shared-decision making are:

[OpenTalk](#)- co-created by Common Room, the Anna Freud Centre and young people, Open Talk is an decision-making model for CAMHS which provides a practical framework for CAMHS practitioners to build on their existing skills and expertise to reflect on how decision-making with young people can be more open, visible and explicit.

[Choice and Partnership Approach \(CAPA\)](#) is a clinical service transformation model that brings together:

- Collaborative practice: the active involvement of young people and their families
- Goal setting with regular review involving the young person
- Demand and capacity ideas and Lean Thinking
- A new approach to clinical skills and job planning: skill-mix layering

[i-THRIVE Grids](#): These decision aids have been co-created with service users, experienced clinicians, i-THRIVE Community of Practice members, educators, researchers, and other experts working with children and young people. The grids are grounded in the THRIVE framework for conceptualising need. The grids have been developed by the Anna Freud Centre, funded by the Health Foundation

[Child Outcomes Research Consortium \(CORC\)](#) is a learning collaboration of mental health specialists from services working with children and young people with mental health and wellbeing difficulties. The collaboration is dedicated to ensuring that outcomes important to service users are at the heart of service provision and planning. Members collect information from children, young people and families on progress, outcomes and experiences of care received. The data is collected, explained and interpreted with young people in mind and CORC members are committed to using this information to reflect on service provision and improve practice.

[Goals and Goal Based Outcomes \(GBO's\)](#) (2013). Law, D & Jacob, J. CAMHS Press: London. Useful information in using goal based outcomes measures with children and young people

What is participation?

Public participation: Common Terms

Experts by experience: 'Experts by Experience are people who have personal experience of using or caring for someone who uses health, mental health and/or social care services' (CQC)

Patient Voice: 'This refers to various ways of ensuring that the voices of patients, carers, families and the wider public are heard in the decision-making process for health services. Activities that promote PPV can include reference groups, workshops, surveys and consultations.' (NHS England)

Community engagement: 'Community engagement encompasses a range of approaches to maximise the involvement of local communities in local initiatives to improve their health and wellbeing and reduce health inequalities. This includes: needs assessment, community development, planning, design, development, delivery and evaluation.' (NICE)

Co-design: 'The process of designing a service or product with people that will use or deliver it' Source: www.designcouncil.org

Co-production: 'Co-production is a relationship where professionals and citizens share power to design, plan, and deliver support together, recognising that both partners have vital contributions to make to improve quality of life for people and communities.' (National Co-production Critical Friends')

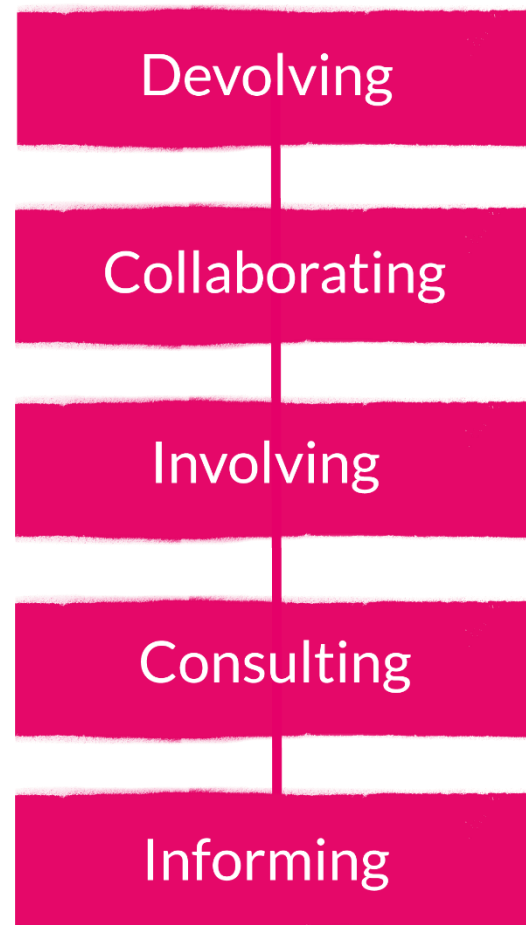
Youth Engagement: 'Youth engagement is the result when young people are involved in responsible, challenging actions to create positive social change. This means involving youth in planning and in making decisions that affect themselves and others.' (Act for Youth)

What is participation?

Levels of participation

Is participation: **adult-led, youth-adult partnership or youth led?** The most common forms of participation in children and young people's mental health are usually a youth-adult partnership e.g. shared-decision making and co-production. This level enables both sides to equally influence outcomes with their expertise so that decisions are safe **and** person centred.

The '**ladder of participation**' is often used to think about the extent to which power is moved from the hands of the professional workforce to the children, young people and families living in local communities. Participation- whether individual or public will usually move across the different levels over time in response to changes in focus and changes in the mental health of those involved.



Adapted from Arnstein's
'Ladder of Participation'

Children, young people and families:

have direct control over resources for example personal health budgets, tools to promote self-management, participatory budgeting

work in partnership with professionals to identify problems, set goals and design solutions for example use of goal based outcome measures, service co-production

are consistently and systematically represented within decision-making processes for example participation groups, as representatives on partnership boards, service evaluation

give feedback that influences decisions being made for example experience surveys, focus groups, pupil surveys

can access information about decisions impacting them for example through posters, websites

What is participation?

The table below gives some common examples of what individual and public participation might look like at each level.

	Individual Participation	Public Participation
Devolving	Young people have their own personal budgets and are able to determine the best care for them, with expert input and support from professionals.	A group of previous service users initiate a project to provide peer support to young people transitioning out of services. The commissioner provides resources for their programme including resourcing for support from clinical staff to ensure the programme is safe.
Collaborating	Young person and practitioner develop and agree a transitions plan together and continue to actively review progress with both working to identify and address any challenges in partnership. Young person understands and feels ownership over the plan.	A service sets up an experience based co-design group and young people and staff work together to identify issues in the service, engage other users in designing solutions and staff and young people together implement and evaluate the solutions
Involving	Young person is involved in the conversations about their care plan and it is then prepared, taking their views into account and they are given a copy	A shadow youth steering group informs the development of a new schools mental health prevention scheme. It routinely meets with the programme steering group and informs decisions.

The levels below this line are not considered to be participation as they don't genuinely shift any control to children and young people. However, there are situations where these levels may be most appropriate (see the next page for more details) but even in these situations, progress can often be made towards higher levels of participation in partnership with young people.

Consulting	Young person able to give feedback about their care via a feedback form but they aren't actively involved in resolving any issues they raise	Service users attend a participation group and give views on changes need to service décor, these are fed back to senior management who decide how much of a priority they are and what will happen
Informing	Leaflet available for young people about what the service offers	A poster in the waiting room notifying changes to service opening times

Levels and dimensions of participation

When designing participation, the level (e.g. the extent to which children, young people and families have influence and power) is not the only important consideration. Other aspects have been set out by Kirby et al (2003), in their list of 'dimensions of participation'

1. level of participation
2. focus of the decision-making
3. content of the decision-making
4. nature of participation activity
5. frequency and duration of participation
6. characteristics of children and young people involved

We can consider all the dimensions by asking questions like:

Focus of decision-making: who is this decision about and who else will it impact? Who will need to play a role in supporting the implementation of whatever decision is made?

Content of decision-making: what is the scope of this decision and how much risk is associated with this decision? What resources are implicated in this decision?

Nature of participation activity: what will being involved look like? What amount and type of information needs to be communicated and understood? Does the decision need to be made now or is there time for consideration and multiple conversations?

Characteristics of children and young people involved: how do the young people involved prefer to communicate? Does this decision feel significant to them? Do they want to be involved? What factors might impact their decision-making?

Asking these kinds of questions can help balance out the different factors and help us come to an informed decision about the best level of participation at a given time. However, the level of participation needs to be considered in each instance of decision-making, taking all of these dimensions into consideration once again.

What is participation?

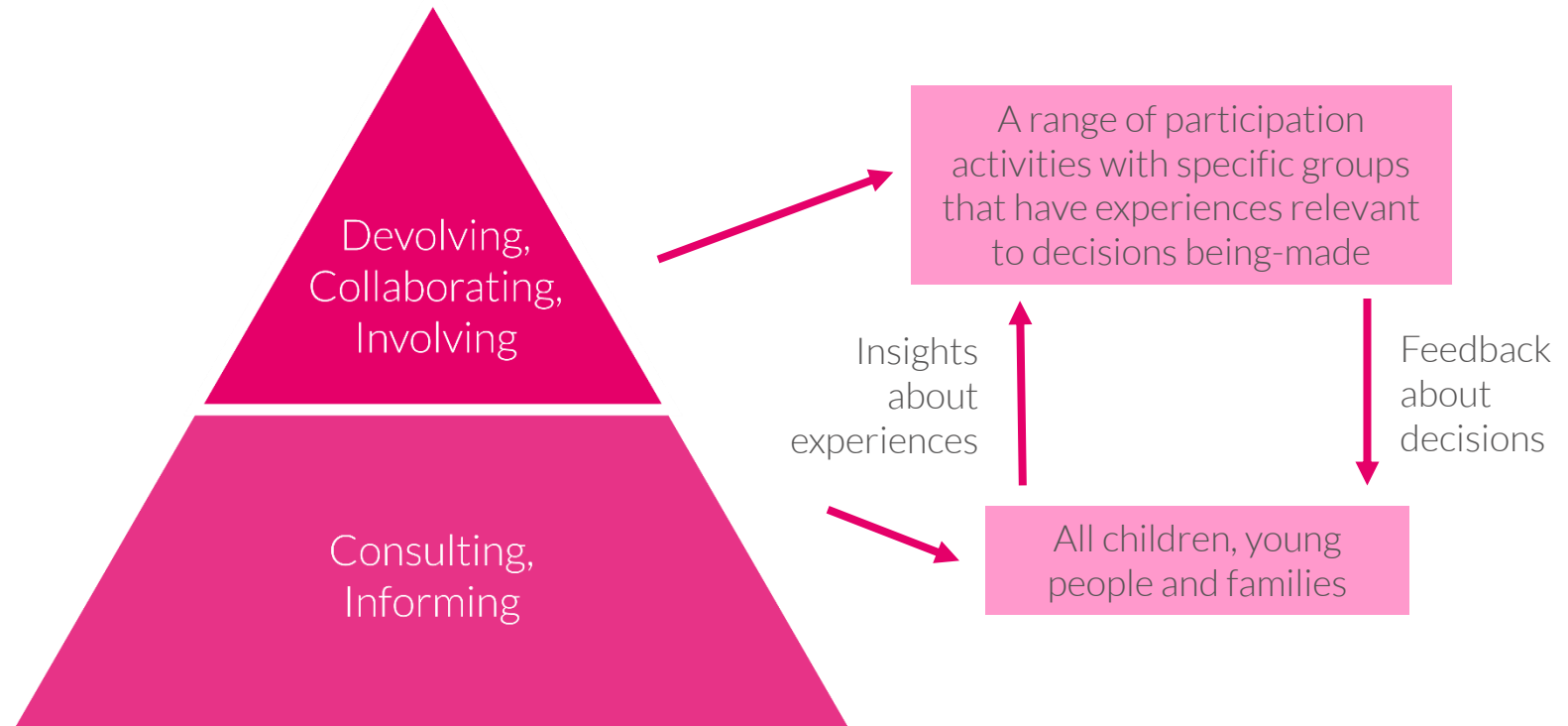
Levels of public participation

Designing good public participation involves working out which groups of children, young people and parents and carers need to be involved in what stages of decision-making and to what level at each stage.

Sometimes value comes from having high numbers of people involved- this is especially useful for example when assessing needs across a group and prioritising issues. At other times value comes from a smaller number of people being very involved so that they have a good understanding of all the issues and a consistent voice in decisions.

Many process of public participation move between these two approaches to achieve a balance of breadth and depth of children and young people's voice.

A typical structure for public participation across a local system could be:



Amplified is about building participation right across the children and young people's mental health system through providing participation training and consultancy, sharing good practice across the country and promoting access to participation tools and resources.

It is an NHS England funded programme, led by YoungMinds and NEL Commissioning Support Unit.

Visit: www.youngminds.org.uk/amplified to find out more or email: amplified@youngminds.org.uk if you have any questions.

Amplified Training and Development

The Amplified training and development programme provides participation focussed capacity building for NHS England funded organisations working in children and young people's mental health, including: mental health services (community, inpatient, community eating disorder services), clinical commissioning groups and clinical networks, health and justice commissioners, education settings, local authorities and children's services and youth justice settings.



There are three levels within the training and development strand:

Grounding Resources providing foundation knowledge about participation in children and young people's mental health and signposting to other useful participation resources.

To access the Building and Applying events and resources sign up to the Amplified professional Voices network: [LINK](#)

Building Practical guidance on delivering the nine CYP-IAPT participation principles delivered through webinars and resources. The focus is on showcasing practice from within the system and promoting conversation and shared learning between professionals, children and young people and parents and carers around participation in mental health.

Applying Setting and profession specific participation events, resources and webinars aimed at addressing the specific types of participation in mental health services; commissioning; youth justice and education- with a focus on peer learning and leadership. Delivered in partnership with services and other partners across the system.



Transforming participation across young people's mental health

youngminds.org.uk/amplified

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