

Supporting the participation of children and young people experiencing extra vulnerabilities

A toolkit for professionals working in mental health settings

About this guide

This toolkit has been created by children and young people, parents and carers and professionals as part of Amplified, an NHS England funded programme to promote participation in children and young people's mental health.

The toolkit is for anyone working in, or interested, in participation in children and young people's mental health. It aims to be relevant to all of the different organisations involved in children and young people's mental health, including:

- Community mental health services
- Inpatient mental health services
- Schools and colleges
- Voluntary and community organisations
- Local Healthwatch
- Youth offending teams

The aim of the toolkit is to support organisations across the children and young people's mental health system to increase the participation of children, young people and families experiencing vulnerability by:

- Presenting the perspective of young people and parents on vulnerability and how it impacts their experience of services, and their engagement with participation opportunities
- Presenting practical tools you can use in your organisation to:
 - ✓ Identify more vulnerable groups in your community
 - Understand the needs and experience of these groups
 - Involve these groups in improving mental health services to better meet their needs.

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Foreword

By Lorna R Amplified Youth Advisor

Almost everyone acknowledges the importance of ensuring that the most vulnerable young people – who have to overcome more obstacles than most – can access mental health support. But the Amplified programme is driven by an additional belief: that it's also essential to include the most vulnerable young people in making decisions about their own care and the services they use. We want to make positive changes to services supporting all young people, and this starts with feedback from those who find them most difficult to engage with.

Through the work of the Amplified Trailblazers, Youth and Parent Advisors have explored what professionals need to be aware of when working with children and young people experiencing vulnerability. We know from experience that:

- Vulnerability comes in many different forms.
- Vulnerabilities do not define any young person.
- Vulnerability is not necessarily static and people can move into and out of vulnerability.
- Vulnerability is not necessarily outwardly visible.
- Vulnerability can appear in unexpected places and ways.

It is so important to make sure that everyone is included in their own healthcare, but when thinking about the difficulties this might involve for young people experiencing vulnerabilities, one reoccurring theme is in confidence. A lack of self-esteem can cause people to engage in more dangerous behaviours.

Classifying young people according to their 'extra vulnerabilities' is useful to see the framework from which young people are viewing their world, identifying extra risks, and allowing further explanation and empathy towards their behaviours. It is also important in enabling young people to understand their rights and what they are entitled to.

However, it's also important to view young people as individuals, just like anyone else. Every person is vulnerable at different times in their lives. We need to allow young people to disclose their 'vulnerabilities' at times that suit them, and for healthcare professionals to acknowledge that vulnerabilities are not constant, and that new situations and aspects may emerge later which also need to be considered. Young people are multi-faceted, and the services that support our mental health need to reflect this.

"Young people are multifaceted and the services that support our mental health need to reflect this."

How we created this guide

1. Recruit Trailblazers

We selected eight organisations ('Amplified Trailblazers') from across England to work with the Amplified team around increasing the participation of groups experiencing vulnerability in their organisations for six months. Groups that our Amplified Trailblazers wanted to increase engagement with included:

- Young people with learning disabilities
- Black, Asian and minority ethnic (BAME)
- Lesbian, gay, bisexual, transgender and queer or questioning (LGBTQ+)
- Young people with autism
- Young men

They were supported to develop specific elements of their participation work, sharing their learning with each other as they improved their engagement activities. At the end of six months, we facilitated learning throughout the wider mental health system through toolkits, learning resources, and best practice case studies.

2. Generating knowledge

Young people and/or parents from each Amplified Trailblazer participated in mapping workshops to explore the idea of vulnerability and how it impacts access to services, and participation. Over 80 young people participated across the workshops. We also interviewed and held discussion groups with staff in the Amplified Trailblazer organisations about their experience of delivering services to, and undertaking participation with, vulnerable groups.

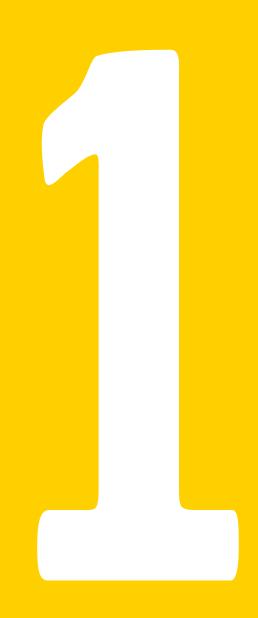
Each Amplified Trailblazer then undertook its own project to:

- Increase the participation of the vulnerable group they had identified with their organisation and/or
- Involve the group in co-producing an intervention to improve the experience of that group when accessing mental health services.

3. Analysis and sharing learning

The Amplified team of staff, young people and parents and carers brought together the insights from the workshops and interviews – as well as information from the Amplified Insights surveys of these groups to generate the steps and learning in this toolkit.¹

 $^{1\}quad Young Minds (2018) Amplified Insights Survey: https://youngminds.org.uk/media/2152/amplified-insights-survey-2018.pdf (2018) Amplified Insights-survey-2018.pdf (2018) Am$



Section 1: Understanding vulnerability in relation to children and young people's mental health

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Understanding vulnerability in relation to children and young people's mental health

This section explores the idea of vulnerability from the perspective of professionals, children and young people, and parents and carers in the mental health system. The information is taken from workshops with participants in Amplified Trailblazer projects, and built on with wider insights from the Amplified participation surveys and existing evidence about the experiences of vulnerable groups.

What do we mean when we say vulnerable?

'Vulnerability' is a word used in health policy to describe groups who are **more** likely to experience health problems and less likely to be able to access the health support they need. In children and young people's mental health, providing care for the most vulnerable children and young people was one of the key priorities in the government's Future in Mind guidance which highlighted the importance of designing mental health services around the needs of these groups.

Vulnerability is closely linked to **health inequality**. We all want all children to have the best mental health possible, but we know there are disparities between how likely different groups of children and young people are to experience mental health problems- and to be able to get help when they need it. These disparities are noted within the Long Term Plan and the Equalities Act 2010 and taking action to tackle them is an important priority for the government, for NHS England and NHS Improvement, and for local commissioners.



"There are some children and young people who have greater vulnerability to mental health problems but who find it more difficult to access help. If we can get it right for the most vulnerable, such as looked-after children and care leavers, then it is more likely we will get it right for all those in need"

Future in Mind,
Department of Health, 2016

Which children and young people are vulnerable?

Health and equalities policy include the following groups as potentially vulnerable:

- Young people from low income families
- Children with experience of the care system
- Children with experience of the justice system
- Young carers
- Young people who have been sexually abused and/or exploited
- Substance misusing young people
- · Lesbian, gay, bisexual young people
- Trans young people
- Young people who have experienced abuse/neglect in any form
- Black, Asian and minority ethnic (BAME)
- Children with special educational needs
- Children with neurodiverse conditions like ASD and ADD
- Children with refugee and asylum seeker status
- Children and young people who have experienced domestic violence in the home.

Professionals responding to the Amplified survey also included the following groups as vulnerable:

- Children and young people whose parents are affected by drug/alcohol abuse
- Children and young people who have experienced loss/bereavement
- Young people whose parents are affected by mental health issues
- Children and young people whose parents are in prison
- · Teenage parents.

It is important to remember that these lists don't mean that every person in any one (or a number) of these groups is vulnerable – they are just some of the main risk factors for vulnerability.

The types of experiences that can contribute to vulnerability are often called 'adverse childhood experiences' (ACEs). ACEs are "highly stressful, and potentially traumatic, events or situations". These experiences include: prejudice (like LGBT+ prejudice, racism, ableism); abuse and neglect; deprivation and poverty; traumatic bereavements and violence such as domestic abuse or gang membership. Studies show that 9% of children and young people experience four or more of these adversities. These young people are four times more likely to have low levels of mental wellbeing and life satisfaction, than their peers who experience no adversity.

 $For lots\ more\ information\ about\ adversity,\ see\ Young Minds'\ Addressing\ Adversity\ guide.$



The types of experiences that can contribute to vulnerability are often called 'adverse childhood experiences' (ACEs).

ACEs are "highly stressful, and potentially traumatic, events or situations".

How do young people feel 'vulnerability' impacts their access to mental health services?

Amplified Trailblazers created fictional user journeys with young people experiencing some of the vulnerabilities mentioned to find out whether and how young people feel vulnerabilities can affect their experience of and access to mental health services. Six groups of young people created these user journeys and identified barriers to accessing support they felt wouldn't be there to the same extent, or at all, amongst peers who didn't share their experiences. These were:

- Lack of self-esteem and not feeling worthy of help
- Behaviour they feel is them asking for help, instead being seen as difficult by adults
- Not understanding mental health and therefore not realising there is support available that could help them
- Social isolation meaning they don't have peers or trusted adults to ask for help or to support them go to an appointment
- Fear of discrimination from services and professionals
- Having pressures in their life that feel more urgent than seeking help or going to appointments
- Not being able to get to appointments due to lack of time, not feeling safe or not being able to travel to the venue where the appointment is
- Having more complicated needs so feeling there are fewer services available that can actually help them.

How do young people feel that vulnerability impacts their participation in mental health services?

The fictional user journeys were also used to explore how young people felt vulnerability impacted their participation in mental health services. The groups generated lots of barriers and Amplified Parent and Youth Advisors worked with the Amplified staff team to categorise them. We developed four groups of barriers to participation that are related to vulnerability:

- **Interpersonal barriers** between the young person and professionals e.g. a lack of trust in adult decision-makers due to past experiences of being unheard and let down
- **Personal barriers** within the young person e.g. lack of self-esteem leading to belief their views don't count and they have nothing to offer
- **Structural barriers** e.g. they don't have the time to attend meetings, it isnt safe to attend and/or they can't afford to wait for expenses to be reimbursed
- **Institutional barriers** e.g. prejudice or stereotyping means that the needs and behaviours of some groups are less understood, so services don't design participation opportunities in a way that is accessible and appealing to them.



A lack of understanding about mental health, and not realising there is support available, can hinder young people's access to services

Young people's views were also reflected by professionals who responded to the Amplified survey. Professionals felt there were groups of young people who were far less likely to participate within their service and these included:

- Young people with communication difficulties
- Young people with disabilities
- Young people who are not currently in school or education
- BAME young people and young people from Traveller Communities.

Some respondents explained why they felt these groups didn't take up opportunities to participate and two the most common reasons are summarised in the following quotes from survey respondents, summarised as:

- 1) "General mistrust of services"
- 2) "Cultural barriers and different understandings of mental health".

This suggests that in many services there are big opportunities to do more work with vulnerable groups to understand their perspectives and needs. This can lead to these groups helping to redesign ways of working to close the cultural gap between the way services are run and the communities that they serve. In turn, this is likely to build trust between the participating vulnerable groups and services.



There are big opportunities to do more work with vulnerable groups to understand their perspectives and needs



Using the word vulnerability

Overwhelmingly, the young people who participated in the Amplified Trailblazer workshops didn't like the word vulnerable. They knew which groups of young people this phrase often referred to and felt that it was mostly used in negative ways about young people to imply they are:

- Powerless and helpless
- Weak and unable to look after themselves
- Irresponsible.

Some professionals who responded to the Amplified survey also said they didn't like the word because – in the words of a CYPMH worker respondent – "it suggests the vulnerability is inside the child, but it's around them, in society."

However, the groups of young people and professionals agreed that it was useful to have a word like 'vulnerable' that could be used as shorthand for describing children and young people who might have some similar experiences and needs. They felt that it was important for people to be clear that children and young people experience vulnerability and are 'made' vulnerable – and that 'vulnerability' isn't just something people are born with.

"It makes it sound like you're incompetent, dependent on other people...."

"It's a professional term
— people around you use
it about you."







DOs and DON'Ts for professionals working with children, young people and families experiencing vulnerability

By Amplified Youth Advisors

DON'T

- Assume that what makes me 'vulnerable' is the only cause of my issues
- Use what makes me 'vulnerable' as the only or main factor in deciding what help I'm given
- Treat what makes me vulnerable as though it's the only part of my life that I'd want to talk about



DO

- Remember that things around me and that have happened to me have made me vulnerable, I am not just 'vulnerable'
- Understand that my 'vulnerability' might not always be visible
- Realise that how vulnerable I am at any time depends on the situation I am and the people around me- it's not the same all the time
- Use the idea of 'vulnerability' as a tool to help me to understand my right to have my needs met and have the same opportunities as my peers
- Use the idea of 'vulnerability' to help other adults understand reasons behind my actions.

Vulnerability and participation in mental health

Supporting the participation of vulnerable groups can help us proactively take action on health inequality in children's mental health through:

- 1. Enabling more effective planning by being able to better identify future need. This supports the local health economy to make best use of resources, rather than having to respond reactively to emerging crises and needs
- 2. Improving access of groups experiencing vulnerability to health services by co-designing services with them. Increased access to the right support could contribute to improved health outcomes. Similarly, involving groups in designing services could contribute to an improved service experience
- Benefits delivered to groups experiencing vulnerability through the process of participation. These are set out in the NICE guidance on community engagement.

To ensure that the most vulnerable children and young people get their mental health needs met, we need to find ways of designing and promoting mental health support that work for them. This requires understanding the experience of these groups – especially how 'good mental health support' would look through their eyes and then redesigning how we work to deliver this.

"It's that thing about getting people into the room. Finding time to meet with a family. Getting people out of the house and getting to events is difficult, so we try to engage in other ways."

- Routeways

Current Challenges

Children and young adults who experience vulnerability:

- are at greater risk of experienceing poor mental health
- find it harder to access support they need
- often have their needs spotted late and when earlier chances to help have been missed
- have poorer health outcomes than their peers
- are less represented in decisions about services

Increasing the participation of children and young people experiencing vulnerability in the design and delivery of the services they use can:

- Make services feel more accessible and relevant
- Build relataionships and trust between groups experiencing vulnerability and service providers
- Generate positive outcomes for young people e.g. through developing their skills and interests

Services that are co designed with children and young people to be more accessible and relevant to them could be more likely to:

- Increase young people's engagement with services/support
- Help ensure young people are able to access support early and easily
- Offer a better experience to children and young people
- Help children and young people achieve goals and outcomes that matter to them

What we want to achieve

- Improve mental health outcomes for children and young people experiencing vulnerability
- Reduce inequalities in health outcomes between children and young people experiencing vulnerability and their peers



Section 2: Principles for engagement

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Principles for engagement

This section explores practical ways to approach engagement and participation with children and young people experiencing vulnerability using lessons and tools developed with Amplified Trailblazers.

Principles for engagement

1. Relationships matter

Putting in the time and effort to build positive relationships and trust with groups that are not engaging is essential; it doesn't happen quickly.

"Many of those who have the most to contribute need space, time and support to share their views and experience. They need to trust those involved and know their views will be valued and respected." Oxford Health

"Empathy is vital...being very accepting of difference – our young people were very honest, more so than you get in the mainstream." Solihull Council

2. Realistic resourcing

Engaging more vulnerable groups may take time and different approaches may need to be tried, so it is vital that staff resource and activity budgets are realistic if you want to be successful.

"You need patience!" Solihull Council

"Be realistic on the level of resource required to establish and maintain the networks." Greenwich CCG

3. Working across systems

Fostering partnerships with individuals and organisations that already have trusted relationships with the more vulnerable groups you want to reach is a great way to reach groups that aren't yet engaging- but ensure you take a partnership approach and find mutually beneficial ways to work together.

"This is part of a broader strategy, supported by a core group of representatives from CAMHS, Public Health, Education and young people, as well as a wider reference group of representatives." Oxford Health

4. Flexibility

Young people who are experiencing vulnerability may face additional barriers to participation, so particular flexibility is needed to both find forms of engagement that are right for individuals and to adapt engagement over time as young people's motives, confidence and skills develop.

"While it may have seemed that a workshop session would be the best way to get feedback, it was clear that some of the young people weren't as confident in discussing such an emotive subject and required more prompting or the opportunity to discuss one-to-one. Therefore although it takes more time, it is critical to understand individual motivations and needs and tailor our work around this." Greenwich CCG

5. The right space

There are lots of environmental factors that impact how safe and welcoming a space feels to different young people. Ensure the groups you want to engage are involved in designing the space they will use and that, where possible, participation takes place in spaces that young people are already familiar and comfortable with.

6. Peer Leadership

Involving individuals from the groups you want to engage, for example as Peer Workers or Champions, is an effective way of building new relationships with individuals from those groups. Additionally, paying such workers or offering clear incentives can help engage individuals in the first place and assist in overcoming some of the barriers to participation.

7. Start where people are at

'Mental health' and 'participation' are not ideas that every young people will immediately understand or want to associate with. To engage more vulnerable groups consider developing projects that offer a more indirect way for them to share their ideas about services, for example arts based projects or projects about locally important topics that relate to mental health.



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Section 3: Engagement

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Engagement is about how we reach and enable the right children and young people to participate. This involves:

- 1. Working out who needs to have a say and designing strategies to reach them
- 2. Facilitating people in determining how they want to participate, including making adaptations and providing support that they might need
- 3. Sustaining people's involvement across the span of the participation project/role by working collaboratively and flexibly with them.

There are lots of tools we can use to support engagement. The tools shared here were all developed and tested with Amplified Trailblazers. If you are just getting started with engagement or are struggling to reach particular groups, you might use this section as a step by step plan at first. However, you can also pick and choose aspects that you think will build on your existing engagement strategies.

All of the information you will gather through these activities will fit within the example engagement plan found in Section 5 of this document. This is a great way to gather all of the information together and communicate it to colleagues and partners.



There are lots of tools we can use to support engagement

Planning your engagement

Which groups of children and young people do you need to engage?

Begin your engagement planning by mapping out who needs to have a say in your service. Start this by listing the groups in your community. Once you have a list of all the groups in your community, plot them on an engagement map, an example of which you can find on the next page. This is a quick way to prioritise which groups you need to engage for your current participation work.

Understanding who is in your local population will enable you to:

- Design services that meet the needs of this whole population
- Recognise who is not accessing your service and take action to address this.

To access information about the children and young people in your local area, there are lots of public documents you could search for and check. These should all have information about your local population of children and young people and what vulnerabilities are present in your local population.

These documents include:

- Local Transformation Plan (LTP) for your area
- Sustainability and Transformation Partnership (STP) plans for your area
- Local authority's Joint Strategic Needs Assessment and Health and Wellbeing Strategy for your area.

The data in the documents listed above will usually have been taken from the National Child and Maternal Health Intelligence Network.²

Example Engagement Map

	Prevention and early intervention	Targeted support	Specialist and crisis support
Foster carers			
BAME families			
Bangladeshi families			
Same sex families			
Parents with LTCs			

2 Public Health England

What do you know about them already?

When you know which children and young people you need to engage, it's important to take stock of the information you already have about each group. Vulnerable children and young people are at particular risk of 'consultation fatigue': the cycle of being asked the same questions again and again but not experiencing a corresponding improvement in the services they access.

This usually happens because vulnerable children and young people have more complex needs that require them to go to multiple services. If those services are not joined up in their approach to participation, there is a risk of duplicating activities with children and young people.

If you have the time and resources it's a great idea to bring together local services to map what participation they already deliver with vulnerable groups and what insights (such as feedback, information about experiences) they have about them. Many participation reports and resources are published publicly, and partners can easily signpost you to them. For information partners have that isn't public, it's key that young people have agreed for any reports from their participation activities can be shared.

On page 37 there is an Information Map which can be used as the basis for a workshop with partners (write it up on a flipchart and give out post-its) or you could use it to audit your own organisation.

As well as bringing partners together, you could:

- Carry out a review of participation across the local area with the groups you
 want to engage e.g. by contacting and visiting services that work with these
 groups.
- Meet colleagues in other organisations that work with the vulnerable groups you want to engage to find out what approaches they find successful and whether there is anything they are doing that you could link into. One way you could do this is by attending a coffee morning they run to speak to their service users.

What resources and support do you have for engagement?

Time

One of the tips that Amplified Trailblazers gave us again and again about engaging vulnerable groups experiencing vulnerability was 'Be patient!'

Leave as much time as possible at the start of your participation project for engagement and don't expect to have everyone you need in the room right away. It may take multiple meetings for a group to get to the desired mix of people and



Vulnerable children and young people are at particular risk of 'consultation fatigue': the cycle of being asked the same questions again and again but not experiencing a corresponding improvement in the services they access.



Leave as much time as possible at the start of your participation project for engagement and don't expect to have everyone you need in the room right away size and it's not uncommon to need a few months to really establish engagement with a new group.

If you don't have much time and there are lots of vulnerable groups you want to reach, another Amplified Trailblazer tip is to pick one or two vulnerable groups and focus on engaging those to start with. This will allow you to refine your engagement strategies: putting all your energies into relationships with one or two groups will achieve more, our Amplified Trailblazers say, than trying to reach everyone at once.

Senior support

You need to enable your senior managers and leaders to understand how important engagement is. They simply might not realise how long it can take to initially engage more vulnerable groups and that really short timeframes for organising participation activities is likely to only lead to the 'usual suspects' turning up again.

All those involved in children and young people's mental health have a duty to improve care for the most vulnerable – it's a key NHS England and NHS Improvement priority. To do this, we have to listen to and understand the needs of these groups. Framing your engagement plan in terms of how you can help colleagues achieve the standards and requirements set out by policy could help encourage leaders to support any requests you might have, e.g. for longer timeframes or a bit more budget for engagement.

Budget

Most engagement activities do require some resourcing, for example travel costs for workers to visit different partner organisations or money to hold a community event or develop some fun materials for a stall. While the key thing in engagement is relationships (which are free!), realistically your engagement plans will be very limited without at least some budget. Work out in your planning stage what budget you have for engagement and keep this separate from the costs of the actual participation activities that you plan to run once everyone is engaged.

What would motivate your target groups to engage and participate?

"We've learned the importance of being involved in different ways at different levels in a more inclusive way. Some young people are very active and want to be part of a group. Others would rather comment on a Care Plan format." – Cumbria Children and Young People's Multi-Agency Partnership

Children and young people engage and participate for their own reasons. Thinking about the benefits of participation for children and young people and the motives they may have for engaging is vital at the planning stage.



Work out in your planning stage what budget you have for engagement and keep this separate from the costs of the actual participation activities

The best way to find this out is to ask them. Visiting groups you hope to work with through partner organisations is a great way to hold an open conversation to see what young people's perspectives are on participating and what they want to get out of it.

For some people, the opportunity to be heard and feel their actions are making a difference is a reward in itself, however there are other ways to thank participants for their input. Vouchers, prizes and meals are good options but also consider helping participants to develop their skills or offering references and certificates to help them evidence the work they are doing to future employers or education centres.

As a basic principle, participation should not leave participants out of pocket so expenses should be reimbursed as soon as possible. Any payment made above this will be considered income which can effect tax and benefit status so it is important to be aware of this, especially if offering monetary reward for participation.



Visiting groups you hope to work with through partner organisations is a great way to hold an open conversation to see what young people's perspective are on participating and what they want to get out of it.

MOTIVES FOR PARTICIPATING

Research has found that motivators can be grouped as: intrinsic and extrinsic.

- Intrinsic motives are internal and are centred around the individual's personal motives like wanting to be part of a community, feeling more confident
- Extrinsic motives are external and focus more on things with a clear social value like financial incentives, improvement of employment skills, social status.



Intrinsic motivators

- Self-development eg improved confidence
- Feeling appreciated and valued by others
- Wanting to help other people have a better experience of service
- Wanting to help young people's mental health
- Enjoyment and fun
- Wanting to take action on an issue you care about

Extrinsic motivators

- Developing new skills
- Meeting new people
- Getting a reference and experience from your CV
- Achieve personal goal
- Getting a qualification
- Being able to visit a new area

(Adapted from Kaizen Partnership)

What barriers are there around engagement in your service?

You can map the barriers to engagement that young people in specific groups face using the table below and the causes identified on page 9.

Once you have done this you can create an engagement plan by selecting the biggest barriers and developing actions to reduce them.

Mapping barriers to engagement

What might be intrinsic factors within young people contributing to lack of engagement?

e.g., lack of trust, low confidence, worry about child

What might be structural factors within young people's lives contributing to lack of engagement?

e.g., lack of time, many priorities

What might be structural challenges within the organisation contributing to lack of engagement?

e.g., offer doesn't fit need, lack of leadership support, inadequate or wrong type of resources

What might be intrinsic factors within staff contributing to lack of engagement?

e.g.,unwilling to change ways of working e.g. hours or location, discomfort with difference, lack of confidence discussing certain issues

Designing your engagement

Once you have collected and analysed key information using the tools in the last section, you will be ready to use the information you've gathered to start designing your engagement.

We worked with the Amplified Trailblazers to think about the engagement of vulnerable children and young people as a journey. We then mapped out the steps a young person would need to take to eventually participate within a service. At each of the steps, we identified strategies to increase the chances of young people staying involved and reduce the chances that they decide not to participate. This section introduces the engagement journey developed with Amplified Trailblazers and some of the strategies they tested to engage vulnerable children and young people with their services.



At each of the steps, we identified strategies to increase the chances of young people staying involved and reduce the chances that they decide not to participate.

LEVELS OF ENGAGEMENT

The table below shows different levels of engagement from young people. It's important to remember that not every individual within a group starts off at the same level of engagement, and that the strategies you use to engage individuals will need to adapt to where they are starting from.

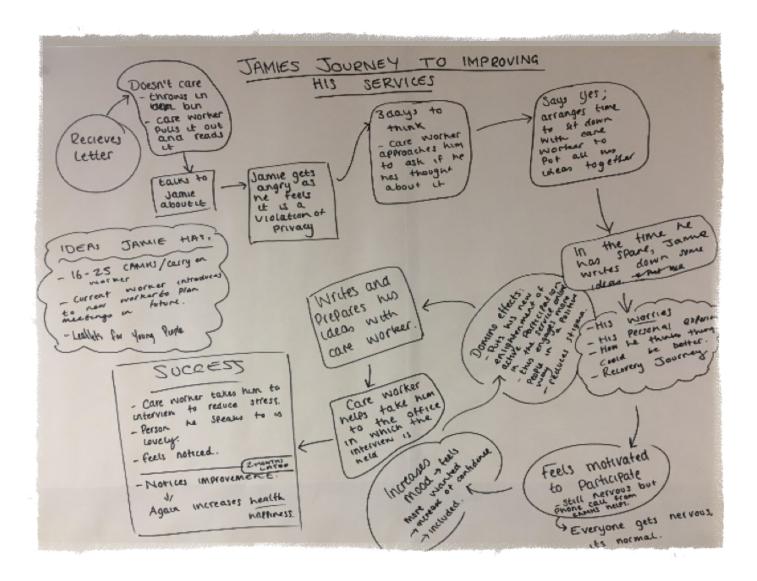
For example, someone with a lower level of engagement like 'reactive' would not be likely to sign up for a volunteer role. However, they may give you feedback about the service if you approach them while they are in the building.

This initial engagement might start to build trust and interest and create a foundation for an ongoing relationship with a participation worker that could be built on over time. All of these levels apply at the 'Participation' stage of the Engagement Journey (see next page) and the levels of engagement could be used as an extra tool to help you plan what types of participation activities the groups you want to engage are most likely going to engage with.

Levels of engagement

Level of engagement	What I do	What I need
Reactive	If there is a specific issue with a service I am using I report it	To know who to report things to
Responsive	I am willing to make myself available to give an option	To be asked and encouraged To know what I say makes a difference
Proactive	I look out for opportunities to share my opinions without waiting for them to be presented to me	To know where to look to find opportunities and information about what the opportunities involve To feel appreciated To have access to the information that will help me contribute my opinion
Supportive	I get involved though doing. I volunteer for specific roles	To know where to look for opportunities and information on what opportunities are open to me Training and information about opportunities I am involved in Someone to help me set limits and not over commit
Generative	I see that something is missing (eg in my community) and I set up my own initiative to address it	Technical expertise where I don't have them Support and encouragement Resources e.g. space, funding

Four steps to engagement



Amplified Trailblazer sites identified four common steps to engagement by thinking about the ideal help-seeking journey for different groups. The ideal help seeking journey activity helps thinking around motivations and barriers to engagement and how this might change at different stages in an individual's journey through mental health services. There is a blank template for this activity in Section 5 of this toolkit.

The four stages are:

- Building awareness and interest
- Induction and planning
- Participation
- Feedback



(Adapted from Kaizen Partnership)

Engagement strategies for each stage of the journey

Building awareness and interest

- Develop promotional materials specifically aimed at target groups
- Identify groups and organisations your target group already engages
 with. You might want to use a circle mapping exercise to start identifying
 some of these (see example of circle mapping in Section 5). Once you
 have identified these groups you could visit them in a service they already
 access to introduce yourself and explain your participation goals.
- Carry out a survey of groups you want to engage with to find out about priority issues for them and how they would want to be involved – you could disseminate this via your own communication platforms and through partner organisations.
- At this stage, there may be very few individuals within your target groups
 who are willing to share their views with you. This is fine! Working with
 them on a one-to-one basis to understand the barriers and motivators for
 their peers and to co-design strategies for participation. Working in this
 way increases engagement with your target groups over time.
- Hold an activity or event for your target group where young people can get to know each other in an informal environment. You could offer incentives such as lunch or gift vouchers for attendance.
- Recruit and train Peer Champions from your target groups to lead engagement with their peers



Induction and planning

- Set goals for individuals' participation and track their progress towards these
- Be clear about what the next steps in the process are
- Explain what each activity involves
- Feedback is important. Ask how participants have found the process so far and get their opinions on the plans you make going forwards.
- Explain what support is available to the project. Set realistic expectations about what can be achieved and how participant's contributions will be utilised
- Agree expectations about how the group will function, including respecting each other's contributions and confidentiality.
- Acknowledge potential barriers to engagement (see page 9-10) and talk about ways to address these
- Discuss and agree with the group how you will recognise and reward young people's participation.



Participation

- Provide support and training to all staff involved in participation
- Develop young people's participation activities in line with their personal goals
- Ensure expenses are paid as quickly as possible, preferably on the same day so young people are not out of pocket
- Stay in regular contact with those who are involved in the project. Remind them about activities and events before the day, and on the day, to support attendance
- Be clear about what will happen if young people disengage e.g. will someone call them? Can they re-join later? – and make sure this happens
- Seek regular feedback about young people's experience of participation
- Visibly celebrate the outcomes of participation with young people and staff
- Keep developing and expanding ways for young people to participate e.g. by bringing new colleagues and teams on board.

Feedback

- Actively encourage feedback at every stage of the participation process
- Offer a range of mediums for feedback including verbal feedback, online surveys or feedback template sent over email. Using different methods helps to ensure young people can give their opinion in a way they are comfortable with
- Make sure you act on young people's feedback and let them know what
 has been done to address it where necessary. This could take the form of
 a "You said, we did" style newsletter. Make sure you ask if they consent to
 being contacted.

Developing your engagement plan

Now you have planned your engagement and selected the engagement strategies you are going to try; it might be useful to pull everything together into an engagement plan. This can help you stay on track, as well as helping colleagues and partners understand who you are trying to reach, why and how. If regularly updated, an engagement plan can be invaluable for teams working in engagement.



Section 4: Delivering your participation activities

Section 2:

Delivering your participation activities

Researchers have explored two approaches to involving vulnerable and/or minority groups within participation processes. Learning from both approaches can also be applied to thinking about promoting access to services within these groups.

APPROACH 1: REPRESENTATIVE APPROACH

- Vulnerable groups are represented within the participation process so they participate in surveys, events etc. with the wider population
- In a service context, this would mean adaptations are made to services to make them more accessible to vulnerable and minority groups
- The needs of vulnerable groups are incorporated into the mainstream demands (including how services should look and feel) with a view to ensuring the overall solutions designed are relevant and accessible to them.

APPROACH 2: ENCLAVE APPROACH

- Vulnerable groups have a separate participation process through which they share their experiences, needs and priorities- this is because of the risk of minority viewpoints being lost in wider population discussions
- In a service context, this would mean designing targeted services or models specifically for vulnerable groups (rather than adapting existing services for accessibility)
- The perspectives of vulnerable groups are represented separately within decision-making processes and may result in separate design of solutions, as well as some integration into solutions for the population in general where criteria for interventions overlaps.

Supporting the safe participation of vulnerable children and young people

Some Amplified Trailblazers shared that colleagues in their organisations were concerned about how to ensure the safety of more vulnerable children and young people when participating in services. These concerns meant that sometimes their colleagues – out of a commitment to managing risk – were less likely to refer certain children and young people for participation opportunities but then these groups missed out.

While managing risk is of primary importance when designing and running any participation activity, it is also important that this is weighed reasonably

against the potential benefits of supporting more vulnerable young people to participate in services and that as many strategies for creating safe participation activities as possible are put in place so that lots of different children and young people can take part.

The table below introduces some of the common strategies that can be used to help ensure safe participation activities.

Safeguarding strategies

Staff focussed interventions Group focussed interventions Development of staff knowledge and skills • Individual member agreement with all participants with content written with participants Conflict management Routine reminders of agreed support precesses with all Facilitation participants and chance for them to ask questions · Sensitive questioning Mental Health first aid • Making it explicit e.g. stating what is and is not safe or appropriate such as contacting other group members if Risk planning distressed Non-violent de-escalation skills • Explicit talk about roles of: participation worker; practitioner, other staff, member of the group Support with intrinsic staff barriers Collaborative group risk planning if starting a new activity • Supervision for participation staff to de-brief • Collaborative group ground rules development Good working alliance between participation and other

Individual focussed interventions

be used and who will have access to them

• Collaborative support planning can use a shared-decision making approach:

Clear precess around how insights from young people will

- 1. Present the opportunity
- 2. Identify together the risks involved and potential benefits
- 3. Present the options for support
- 4. Ask and discuss: "How do the risks, benefits and support options weigh up for you individuality? Is there someone else you can speak this over with?"
- 5. Let's decide together
- Soft intelligence log of things it is helpful for all workers to know (remember to ask permission to log and that YP gave right to see what is recorded)
- Involvement of parent, carers or supportive others in assessing risk and making plans

Organisation focussed interventions

- Increased staffing as and when required
- Change of venue for more safety or accessibility
- Visual reminders of safeguarding process and responsibilities in the space to keep in staff member's minds
- Safeguarding as a routine item in team meetings
- Regular review and updating of policy and processes
- A learning culture, and a no-blame culture



Section 5: Case studies and useful resources

Case study: Devon CYPMHS

About

Only 32% of surveyed LGBTQ+ young people in Devon agreed that they could get enough information about how to look after their mental health.

Why?

"More LGBTQ+ people than heterosexual people are dissatisfied with health services. Experiences of discrimination, heteronormativity, and a lack of information and/or staff knowledge on LGB&T people's health needs are identified as main sources of dissatisfaction. Mental health services are the most often perceived to be discriminatory."

(Hudson-Sharp, N. & Metcalf, H. July 2016)

Outputs from these workshops were used as ground work for the development of an evaluation framework of participation.

Who did the Amplifed Trailblazer want to engage?

- LGBTQ+ young people across the region
- Clinicians and CYPMH service staff from across Devon

"We recognised that in a rural community minority groups can go unseen and feel particularly isolated and discriminated against."

Robin Tay, CYPMH Participation Lead

32%
of surveyed LGBTQyoung people in Devon
agreed that they could
get enough information
about how to look after
their mental health



What happened?

- Young people involved in the CYPMH LGBT+ group co-designed a survey asking about the specific experiences of LGBTQ+ and BAME young people in the region around their mental health
- Project participants researched where to reach peers within these groups and distributed the survey
- The group analysed the responses and using these, and their own experiences, co-designed a training session for CYPMH professionals about the mental health experiences of LGBTQ+
- This session was delivered at a regional CYPMH conference to a diverse audience of professionals

Any challenges?

Pitching the training to CYPMH professionals "without making it seem like we were just criticising the staff and the work they do". The positive feedback from the session indicates this was achieved.

Any good lessons to share?

"It's really helpful if you can get senior members of your organisation on-board with a project as that really encourages young people to know their project is already being well-received and taken seriously."

What's the impact?

- Evaluation from the training indicates participants were more informed and comfortable engaging with people who identify as LGBTQ+ as a result of the session
- Professionals fed back that the session being led by young people and, based on their experiences, made it more impactful and valuable.

"Their [professionals] language has changed"

Case study: Oxford Health

Why?

Around three-quarters of all suicides in the UK are male.

About this area

Between 2007 and 2016, over 300 male suicides occurred across Bath, Swindon, and North East Somerset.

Amplified Trailblazer project

To seek ways to reduce stigma around mental illness by creating a film to encourage help-seeking behaviour amongst boys and young men.

What happened?

Initial consultations with Amplified shaped the content and format of the creative work, including key messages for the film in relation to its audience. Oxford Health then developed a partnership with outside organisations IntoFilm and Suited And Booted in order to create the film 'A letter to my younger self'.

IntoFilm were inspired to take part following work with the Malik Bendjelloul Memorial Foundation, and the partnership saw young participants, parents and community members work alongside professionals in the co-design process

YoungMinds Amplified joined the film's launch event, co-designing promotional strategies with attendees from the local community.

Around 3/4
of all suicides in the UK are male



How will this work be developed further?

YoungMinds and Oxford Health then co-designed a series of workshop activities for both adult and young audiences, in order to help parents, practitioners and school children engage in the topic in a meaningful way.

This will be delivered by members of the Boys In Mind group, including young people, across a range of settings. This builds on Oxford Health's existing 'Positive Mental Health' resource packs for secondary and primary schools.

Any good lessons to share?

"Ensure young people are involved from the outset in agreeing the aims of the project.

Providing a creative focus around something like a film allows relationships and trust to develop early on before young people need to consider sharing more personal aspects of their own experience. It also gives them the option to contribute in a less personal way if they wish. It proved easier to attract young men to activity based and creative forms of participation

Many of those who have the most to contribute need space, time and support to share their views and experience. They need to trust those involved and know their views will be valued and respected.

Some of the young men who shared their experiences were very reluctant to do so publicly and I met with them individually so they could retain their anonymity. In some cases, clinicians initiated these links. I also asked female members of the Participation team to help and they spoke with young men they knew well. We also learned the value of providing opportunities for the young men to meet together as a group but also providing additional opportunities for the female members of the group to join them contribute to the conversation from their perspective."

Case study: Routeways

About

Amplified Trailblazer project Routeways are a Plymouth based local charity that supports children, young people, families and individuals to overcome disadvantage. Working in partnership with CAMHS, they provide parent peer support groups. The focus on their Amplified Trailblazer project was to engage families of children with autism to co-produce resources to support parents and professionals around autistic young people's mental health.

Why?

People with autism are particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life. At least one in three adults with autism experience mental health difficulties due to a lack of support. There are currently around 1,500 children and young people across Devon with Autism.

"It was about hearing parents say the same things over and over again. The struggle to have an identification of mental health issues and effective support alongside young people's ASD diagnosis."

Rose Taylor, Routeways Project Co-ordinator.

What happened?

YoungMinds delivered consultations with parents in order to identify additional support and advice as part of a co-designed pathway structure, providing information for parents and professionals from prediagnosis through to ongoing management

These consultations identified a need for premises – a place for young people to escape to when they felt overwhelmed or needed some space. The focus developed into becoming a mental health & wellbeing hub project, volunteers Rachel and Jade leading this work in partnership with the community.

What's next?

"We have been awarded a grant to provide a range of sensory equipment, to educate others about the importance of supporting the management of sensory needs within this population and set up a sensory room within the already existing Routeways group, to benefit those with Autism and facilitate their engagement in a range of activities. The children have been so excited for this venture to commence after everybody's hard work."

Any challenges?

"It's that thing about getting people into the room. Finding time to meet with a family. Getting people out of the house and getting to events is difficult, so we try to engage in other ways. Getting a collective voice. It's worked and grown because people are passionate about it and want the best for the people who show up – every story we hear is one of fighting for the rights for their child and their family. When people hear of ways to improve that for themselves and other families, then if they can be there they will be."

What's the impact?

Raised the profile for need of this kind of family support:

"I think the impact is that CAMHS in Plymouth are more and more going with this model. Our parent support group (Children's Minds, Families Matter) operates on the understanding that the whole family is affected by a young person's mental health. We focus on supporting parents and siblings to support the young person".

Case Study: Solihull Council

About

A partnership was developed between Solihull MBC and Solihull Action Through Advocacy. The aim was to pilot ways of working with young people with learning difficulties to establish a meaningful pathway for mental health participation.

The overall aim was to deliver insights into what mental health services in Solihull should look like for young people with learning disabilities, and to establish a mechanism for future consultation.

Why?

"To have the young people represented because they do get overlooked – they have a lot to say, and they often have the most important experiences. It may be that they struggle to express how they feel, but it doesn't make their experience any less valid.

We know there is a huge lack of services, especially for young people with a disability and mental health – this is an opportunity to raise that awareness and get something done about it."

What happened?

Amplified supported the project to create and run sessions on mental health awareness and advocacy with a group 16-18-year-olds from a school in Solihull to gain insights into what services they would like to see.

Any Barriers?

"A lack of educational or consultancy resources geared towards young people with learning difficulties and autism – there's a lot out there aimed at young people, but we've had to adapt everything."

For some of the group mental health was a concept that was either new or not well understood and therefore required time and support in order to meaningfully engage in the conversation. Others in the group were better informed, but had lots of clarifying questions.

Any good lessons to share?

"Go in with an open mind. Don't think you're the one with the power just because you're leading the session. It's the other way round; the young people are in charge, not you. They're the ones doing the work!"

- Rebecca Fellows and Lynn Tonks, Solihull Action Through Advocacy

Useful resource: Information Map

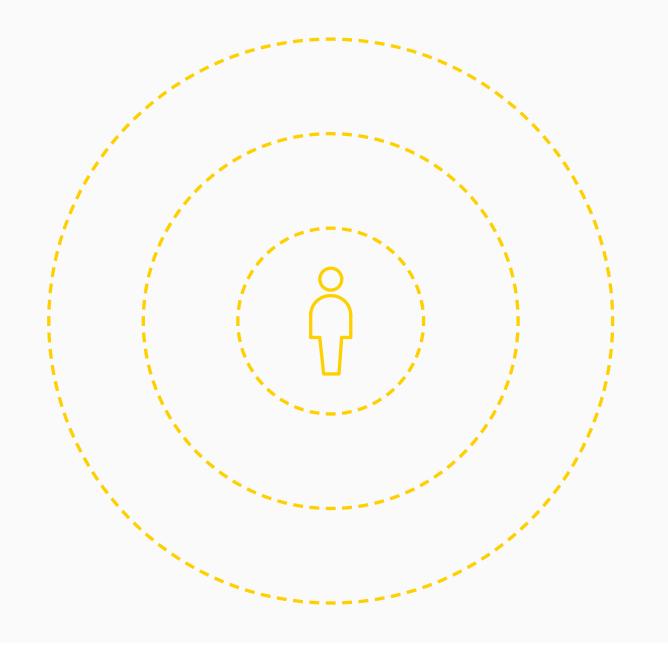
	Which groups?	Information about experience of these groups within mental health system	Information about the mental health needs of these groups	Any other information we have about these groups
Child doesn't need support				
Child and family looking for support				
Child on waiting list for support				
Child accessing service				
Child has been discharged from service				

Useful resource: Circles mapping

Circles mapping is used to think about the people, groups and organisations in a young person's life who might provide support to them.

Try mapping this onto a diagram like the one below. Put those who are the closest to the young person in the inner circle and those who are more distant towards the outer circle.

You could repeat this exercise to think about the different types of service and support that different communities in your local area might access. Once you have done this, you can use these discussions as a starting point to develop a plan about how to engage with them, set goals for individuals' participation and track their progress towards these.



Useful resource: Ideal help-seeking journey for vulnerable young people

JOURNEY STAGE:		
GOAL:		
QUESTIONS:		
AS A YOUNG PERSON I WANT		
	•	

Useful resources

General

- Addressing Adversity: Prioritising adversity and trauma-informed care for children and young people in England, YoungMinds; Bush, M (ed), 2018
- Transforming Together, William, L and Oliva, L, Young Minds, 2018
- Patient and Public Participation: Equality and health inequalities. NHS England. 2016
- Making Health and Social Care Information Accessible. Public Voice Team, NHS England. 2015:
 - Report of consultation, 13 August 09 November 2014
 - Analytical Report on the consultation
- Better Working with Disabled People: The Way Forward, Department of Work and Pensions. 2014
- Involving disabled people: an introduction. Office for Disability Issues. 2010.

Learning Disabilities

- Valuing People: A New Strategy for Learning Disability for the 21st Century. Department of Health. 2001
- Involve Me: Increasing the involvement of people with profound and multiple learning disabilities (PMLD) in decision making and consultation. Mencap, BILD & The Renton Foundation

LGBTQ+

- Trans Men Useful Links. Men's Health Forum
- Action for Trans Health: Campaigning for democratic healthcare
- Falling Through the Cracks: Non-binary people's experiences of transition related healthcare
- Trans Mental Health and Emotional Wellbeing Study 2012. Scottish Transgender Alliance.
- Brighton and Hove Trans Needs Assessment 2015 full report
- Shining the Light: 10 keys to becoming a Trans positive organisation.
 Galop.

- Lesbian, Gay, Bisexual and Trans (LGBT) Health and Inclusion Project
- GP Guide: Supporting Patients Accessing Gender Identity Services, Brighton and Hove Clinical Commissioning Group
- Transgender Equality. Women and Equalities Committee, House of Commons. 2015.
- What's it got to do with you? Stonewall. 2015.

BAME

- How to engage with Gypsies and Travellers as part of your work:
 Leeds Gate Toolkit
- Dancing to our Own Tunes: Reassessing black and minority ethnic mental health service user involvement, Kalathil, J, NSUN/ Afiya Trust, reprinted 2011.
- The "snowy white peaks" of the NHS: a survey of discrimination in governance and leadership and the potential impact on patient care in London and England. Kline, R. 2014.
- Black and Minority Ethnic (BME) Positive Practice Guide. Improving Access to Psychological Treatment (IAPT), NHS. 2009.
- Engaging with BME Communities: insights for impact. BME Leadership Forum, NHS Confederation. 2013
- Involving Black Disabled People in Shaping Services. Joseph Rowntree Foundation. 2001
- Learning Disabilities and BME Communities: Principles for Best Practice.
 University of Birmingham. 2012
- Mental Health Crisis Care: Commissioning excellence for Black and minority ethnic groups. A briefing for Clinical Commissioning Groups. Mind. 2013

Youth Justice

 Unlocking Service User Involvement Practice in Forensic Settings: Research into the provision of service user involvement in secure settings. NSUN/Wish. 2011







About Amplifed

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.



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