



YOUNGMINDS Amplified

**Involving parents and carers
in children and young
people's mental health**

Foreword

Kirstie, Amplified Parent Advisor

Being a parent or carer of a young person with mental health difficulties can be a terrifying, lonely place to be and this is where I found myself a few years ago when my son became ill. As his Mother, all I wanted was for my son to feel better and to know how best to support him. Getting help and negotiating our way through school and mental health services was frustrating and overwhelming, impacting the health and wellbeing of the whole family.

My son needed me to act as his advocate as he found talking to professionals very difficult and in turn, professionals needed my input, along with my son's, to help them understand the depth of his difficulties. As a family we experienced some good care but there were times where better communication and understanding would have made all the difference. In my experience, working together in an honest, supportive and collaborative way is vital to a young person's recovery which is why I feel that parent and carer participation is so important. Alongside improving an individual's care, participation can have a wider impact by using the parent and carer experience as a tool to improve services for others.

As my son's recovery progressed, I felt able to take part in participation opportunities with YoungMinds and my local Children and Young People's Mental Health Service (CYP MHS) service where I have been involved in recruitment. This process was fully supported by a lovely participation worker who arranged for me to attend a recruitment workshop giving me the skills needed to assess applications and sit on an interview panel. After being at home with my son for long periods and feeling isolated I felt anxious and had lost confidence in my own abilities, so for someone like myself, who'd had to give up work to care for their child, the experience was invaluable. I gained new skills and felt that being part of the recruitment process was an opportunity to have a real impact on quality of care in the future. The other members of the panel were able to benefit by gathering insights from myself, who had lived experience and saw things from a parent perspective. Being paid for my time added to the sense of feeling valued and I am currently working on setting up a parent/carer peer support group with my local CYP MHS, something which I feel I would have benefitted from and is much needed in my area.

Participation has allowed me to take control of a very difficult time and use my negative experiences in a positive way. It feels empowering to be working collaboratively with professionals towards a common goal of improving services and support for young people, parents and carers. I firmly believe that meaningful participation is a way of achieving this and hope that this toolkit will give you the inspiration and confidence to commit to embracing parent and carer participation in your own setting.

Contents

Introduction	04
What is parent and carer participation?	05
Benefits of parent and carer participation	06
What do parents need from services?	07
Developing parent and carer participation	16
Levels of Participation	17
Dimensions of participation	18
Types of parent and carer participation	19
Listening events and focus groups	19
Family Days	19
Participation and Support Groups	21
Staff recruitment and training	23
Co-producing resources	26
Commissioning and service design	27
Evaluation	27
Governance	28
Developing a Parent and Carer Participation Strategy	30
Senior leadership support	32
Engaging Participants	33
Representation in Parent and Carer Participation	35
Conclusion	37
Interview with Wendy Minhinnett – Founder, Rollercoaster Parent Support	38
Appendix: Parent and Carer Journey Insights Worksheet	40
Endnotes	41

Introduction

Parents who have had their child experience a crisis in their mental health often describe it as one of the most difficult moments of their lives. By listening to parents, working alongside them and using their experience to develop services which fit both their needs and the needs of young people, professionals have the opportunity to make this experience a little easier.

When a young person and their parent or carer sits down in front of you for an initial appointment, it is the start of the journey for professionals. For parents and young people, it is only one point on a much longer road of getting help.

Parents and carers want to do the best for their child. They feel responsible for making sure they get the right care, but often find the path is not straightforward and finding useful information can feel like navigating their way through a maze. As a result, they often don't know where to turn for help and even when they do, there may be multiple referrals or support options that don't work out. They may feel they haven't been listened to or have had to co-ordinate between different agencies, such as schools or GPs, to get all the necessary information together.

Parents and carers may be nervous about engaging with mental health services, embarrassed that this has happened to their family. They have probably already asked themselves why this has happened, if it's their fault and if there is anything they could have done differently. They may feel guilty that they haven't been able to do more, that they want to help their child but don't know how.

The response and support parents and carers get from the professionals they interact with makes a huge difference to their experience of what comes next. The single most important thing that professionals – from clinical staff to service managers to commissioners – can do is listen to parents and carers with empathy and understanding, and take on board their feedback to make sure that services are responsive to the needs of young people and their families.

Parents and carers can be a significant asset to your organisation if they are engaged, developed and supported to play a meaningful role. This toolkit explores what parents and carers need from services before looking at the different roles they can take within the organisation and the benefits this can provide. It supports the development of a parent and carer participation strategy and the engagement of parents and carers, especially those from a diverse range of backgrounds.

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This toolkit has been created using the work of the Amplified 2018 Trailblazer services, organisations which were supported to improve their parent and carer participation structures, and built on with insights from our parent and carer advisors and the wider

Amplified project. It is aimed at participation leads, service managers, commissioners and senior leadership, as well as any other professionals interested in improving parent and carer participation in their organisation.

What is parent and carer participation?

The participation of parents and carers should run throughout youth mental health services. It is about involving them in the process of their child receiving care and listening to their experiences.

There are two important aspects to parent and carer involvement:

- 1. Being empowered and enabled to play an active role in their child's mental health care**
- 2. Using experience as a driver for improvement and transformation of services and systems** e.g. through involvement in service design, care pathways, workforce training and information creation.

It will not necessarily be appropriate for both of these aspects to happen at the same time. One Amplified parent advisor suggested that parent and carer participation could be viewed as a journey. When a young person is first referred to a service, parents are most concerned with being supported to have the information and confidence to be involved in their child's care. They may be knowledgeable about their child and referral journey but have less understanding of the workings of the wider system.

As their child's care progresses and the situation hopefully moves out of crisis and into recovery, parents are more able to reflect on their experience and get involved in other areas of participation. Many parents will have gained expert knowledge of the system and can use this knowledge to give feedback, improve services and help other parents who are in a similar position.

Parent and carer participation can include a wide variety of activities, but services need to make sure the basics are in place before trying to implement anything more advanced. This can take time. Being able to open up an honest dialogue with parents and carers about their experiences is a building block which needs to be in place before trying to establish participatory governance structures or involve parents in service design.

In some cases, listening to feedback from parents may be hard to hear. The responses may reflect anger or frustration at their experiences. It may feel undeserved if these experiences are not something the service has any direct influence over but it is vital to listen without responding defensively and build a constructive dialogue about ways things could be improved. Listening to where the system has gone wrong can identify weaknesses and help find ways to improve it so that subsequent parents don't experience the same difficulties. Not taking these initial steps towards meaningful participation can mean that parent engagement is fraught with difficulties. Parents and carers who have a negative experience of participation are unlikely to remain involved or see it as a good use of their time. Alternately, parents who have a positive experience of participation are likely to remain involved throughout the journey of supporting their child, and beyond.

Parent and carer participation is about working in partnership with parents. It's about using their experience alongside professional knowledge and working together to give young people the most positive experience of engaging with mental health services. By creating the most effective system to support whole families when they need it, young people who come into contact with services can be enabled to achieve the best possible outcomes.

Benefits of parent and carer participation

Ultimately the benefit of all participation is that it leads to better outcomes for young people. Parents and carers are an important voice because they are often the first people, beyond the young person themselves, to notice that something is wrong. They are likely to be involved in seeking help and responsible for caring for their child when they are unwell. When the journey through care is difficult, it is often parents and carers who will be the ones who will need to try to resolve the problem.



Listening to feedback and understanding where things go wrong gives you the knowledge to get things right and provide the best service possible for both parents and carers and young people. Involving parents and carers in improving services means that the needs of this group are more likely to be met.

As a result, services are likely to experience better engagement and receive less complaints. This means less time dealing with problems and more time to design and deliver good care. Incorporating the unique perspective of parents as experts by experience can lead to ideas for service improvement that professionals may not have thought of on their own.

Participation is increasingly supported by statutory guidance and policy including the NHS Long Term

Plan, Future in Mind and local Sustainability and Transformation Plans. As a result, it is likely to also feature in organisational strategies and ways of working. Care Quality Commission (CQC) inspections will look at both young person and parent and carer participation and it also features in best practice standards like those set out by the **Quality Network for Inpatient CAMHS (QNIC)** or **Community CAMHS (QNCC)**.

Providing professionals with dedicated and appropriate resources, budget and training on participation methods not only helps fulfil these requirements but as a result can increase the confidence they feel in engaging with parents and carers on a day to day basis. Parents whose needs and questions are met are likely to feel more confident and supported in caring for their child's mental health.

What do parents need from services?

When parents and carers are asked about what they need from their engagement with children and young people's mental health services, common themes emerge.

The following information – CIRCLES – is a summary of what parents have told us at listening events, workshops and other events, including the Amplified Trailblazer projects. It is built on with wider knowledge from the Amplified Insights survey and existing evidence about the experiences of parents and carers who come into contact with CYP MHS.



Communication

Getting communication with parents and carers right is the most important element in ensuring that families have a good experience of engaging with young people's mental health services. Communication encompasses everything about the service from the moment of referral and includes information available online, the written communication sent before an appointment and the physical environment people are seen in. Small details, such as having photos of staff in the waiting room, help create the impression that the experience of young people and parents and carers is central to the way a service operates.

It is important that parents are clearly informed about the process of getting help for their child and receive regular updates so they understand what is happening. Parents have said they would prefer services to be honest about how long they are likely to be waiting before they get an appointment so they are able to manage expectations with their child. Being proactive in keeping parents and carers up to date with this information means they don't have to chase services to find whether anything has changed. Having a back-up plan for unexpected delays, such as staff sickness, means you can reassure parents and carers that the support for their child will be there with minimal disruption.

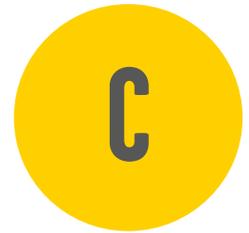
Giving parents a named contact means they know who they can get in touch with if they have any questions, or if something changes with the young person in between appointments, or before they are seen. Parents are best placed to notice a deterioration in their child's mental health but are often left not knowing how worried they should be or what to do about it.

Parents would like to be included in the process of their child being seen by mental health services as much as possible, but feel like they are seen as a nuisance if they ask too many questions or contact services too often. Therefore, the service should take the lead on ensuring parents understand what is happening and they have all the information they need to support their child, including what they can expect to be told and when, and what the limits are around confidentiality.

Parents and carers need to feel that the professionals they talk to are compassionate about the experiences of the family and they aren't being judged for what is happening to their child. Many are often already questioning why their child is unwell and wondering if there was anything they could have done differently. Feeling professionals hold them responsible makes the experience much more difficult.

This was the most important issue highlighted by the Amplified Parent Advisors:

“For a professional to show that they understand how overwhelming and devastating it can be for parents and carers to see their child suffering and how this can impact the whole family feels like a lifeline and gives hope that



“It is only when parents/ carers and young people feel free from judgement that they can feel safe and therefore enabled to contribute on an equal basis.”

Amplified Parent Advisor

the family will be able to work collaboratively with services for the good of their child. It is common that parents have seen many professionals and not all will have been supportive, so a parent may arrive at an appointment with negative preconceptions and a lack of trust. A professional who gives a gentle, non-judgemental and empathetic response makes all the difference between a useful consultation and a frustrating, negative one."

- Amplified Parent Advisor

The impression the service creates through its communication with parents and carers can make a huge difference to their experience. Investing time in getting this right from the start can mean improved relationships between professionals and parents and carers, positive engagement with the service and better outcomes for the young person.

Information

When a young person starts to struggle with their mental health, parents and carers want to be able to access clear and helpful information. However, many have told us that finding a trustworthy source for this can be a challenge. Parents need information to be easily available, on websites and within the services they access.

Information should be available on both the difficulties their child is experiencing and the process of getting help from mental health services. It should cover the whole of the journey, from what to do if they start noticing problems, to getting help and what to do post-discharge if they recognise that things are difficult, or if they feel their child needs support again. Having a trustworthy source for this information is essential but should also be accompanied by face to face engagement with professionals to answer their questions and explain anything else that feels unclear or needs exploring further.

 **TOP TIP** Parents want this information to be accessible and relevant to their needs, meaning free from jargon and containing practical information on tips and strategies to help them find the best way to support their child. One way of ensuring this is to get parents and carers involved in co-producing the information that is provided. Information should enable parents and carers to understand and exercise their child's and their parental rights when accessing services, especially inpatient services.

Parents look to professionals to recognise that they need to learn the tools that can help them understand what is happening, manage risks and get things right at home so they can give their child the best support possible. Feeling confident that they are doing the right thing is important in ensuring their child's recovery is as positive as it can be.



Relationships



Young people who are struggling with their mental health often have a number of people involved in their care. Their roles are often dependent on each other and how well they join up can have a huge impact on both young people and parents' experiences of engaging with services.

When multi-agency working is successful, the young person's needs remain central and information is shared between professionals as and when it is needed. When it doesn't go to plan, parents report feeling that they need to act as a go-between or care co-ordinator to ensure that the necessary information gets to the right person. This additional pressure can make managing an already stressful time much more difficult.

Outside of the home, the first place a young person's difficulties are likely to be picked up is at school, especially where they relate to learning and development. Young people's interaction with teachers and support staff can be a source of support outside the home, offer a more complete picture of what is going on for them or give insight into their relationship with peers and this can be vital to the assessment and care provided. Schools may need information from other professionals to authorise additional support or manage risk. A breakdown in communication at this stage can adversely impact a young person's education and wellbeing, and create greater problems further down the line.

Once a parent or carer has noticed that their child is experiencing difficulties with their mental health, their GP is the most likely person they will approach for help and advice. GPs often act as the gatekeeper for additional services and need to have a clear understanding of when to make referrals and how the process works. They are also the place young people will be discharged back to after they have received any care from additional services so they play a vital role in a family's journey. GPs need to receive feedback on their referrals, be kept informed during a period of care and given clear instructions on aftercare to ensure their role functions as well as possible and parents are not left to join up the pieces.

Even within mental health services communication between different professionals, tiers or services is vital. When young people see a new professional, they and their parents or carers expect that person to know who they have already seen and to understand why they have been referred. They struggle to understand why they are often asked to retell their stories as this is emotionally difficult as well as feeling like a waste of time.

Keeping young people and their needs central to the management of relationships between services is vital to ensuring information reaches the necessary professionals and the experience for young people and parents and carers is as positive as possible.



TOP TIP

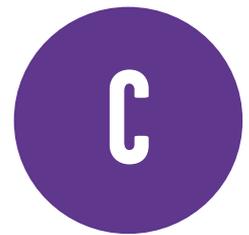
Parents have suggested that identifying a lead professional to co-ordinate these relationships, and improving information sharing processes and collaboration between services would make a huge difference to their experience.

Confidentiality

Both parents and carers and young people have reported that they are unclear about confidentiality and the limits on what information can be shared. Although children and young people have the same rights to privacy and confidentiality as adults, including in relation to information sharing with their parents, this can be difficult for parents who will want to be included in their child's treatment and progress.

Parents and carers often want to understand what is happening so they are aware of anything the service is doing that they can learn from, and so they feel that they are doing everything they can to get things right for their child at home. It is important to give them clear information about what they can be told and what role they can take in the young person's care.

Sometimes a young person will not want their parents or carers involved. If appropriate to the situation and in the child's best interests, the reasons behind this should be explored with the young person and they should be encouraged to share whatever they are comfortable with to ensure their parent can actively support their recovery. If there is information that cannot be shared, parents ask that this is explained to them in a transparent and respectful way so they understand why this is the case and what other ways they can be involved. Investing in good communication early on can ensure the parents feel heard while also protecting the young person's right to confidentiality.

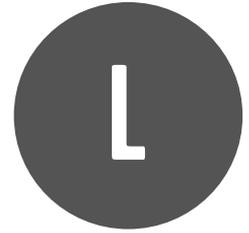


TOP TIP

Parents have highlighted how important it is for them to be given time when they can talk to their child's CYP MHS worker without their child being present.

Parents have told us that they often do not feel comfortable to talk openly and honestly about the difficulties the family is experiencing. Parents want to be positive about their child's recovery when talking to them, but also need a space to be able to give their side of the situation, to inform them of any important information which their child may not have disclosed or discuss how difficult things are without making their child feel guilty.

Listening



Parents want their knowledge about their child to be listened to. Their expertise comes from being there for their child throughout their lives. They have reached a point where they feel like they no longer know what to do and are asking for help. However, they may feel like information they hold about their child's strengths and difficulties, emotions and behaviour is deemed secondary to the young persons, rather than being additional information which helps professionals develop a more comprehensive picture of the situation.

When parents raise concerns about their child, they need services to listen and take them seriously in order to positively and effectively support their child alongside professionals. This means being considered as part of the process of assessment and treatment where it is appropriate, understanding what the options for treatment are and, again where appropriate, be part of the decision making around the way forward. Where a diagnosis is given, parents need to understand what this means and what support will be available. In some cases, parents may not agree that a diagnosis fits their child and it is vital to understand why this is.

For example, parents report one of the phrases they hear in response to their concerns is that their child is ok at school so their difficulties must be behavioural. Parents who have listened to their child and their behaviour may feel that their child tries their hardest to manage during the school day but is no longer able to do this when they are at home. If this perspective isn't considered, treatment may focus on changing the child's behaviour while missing an underlying issue or diagnosis which explains why it is taking place.

Finding the right level of parental involvement is not easy. Some young people may want a higher level of parental involvement if they do not feel confident managing the relationship with CYP MHS. They may want their parent to explain things they do not feel able to, or their parent may need to advocate for them to ensure that their wishes are taken into account.

If the young person is an adolescent, they may be pulling away from their parents and asserting their independence but parents still need opportunities to be listened to, especially if the child is living at home and parents are responsible for setting boundaries and ensuring the young person is safe. If a young person is coming home from leave or being discharged from inpatient care, carers may want to discuss concerns around risk and be supported to think of strategies to manage this.

Listening to parents, understanding their concerns and taking these into account when making decisions is likely to lead to a better relationship between the service and carers, a greater understanding of the young person, and potentially better outcomes as the result of a more informed decision on appropriate care.

Engagement



Despite the difficulties parents and carers are likely to be managing at home, they will often welcome the opportunity to engage with participation activities. The Amplified Insights survey found that 94% of parents thought having more carers involved in service planning could improve the wellbeing of children and young people, while only 23% felt that this would be a burden on their time. The desire to be involved is there, but it requires the system to effectively engage parents and let them know that their voice matters.

One of the major barriers to parents and carer participation is making sure they know the opportunities to get involved are there to begin with. A poster in the waiting room is a good start but encouraging parents that services want to hear from them often means reaching them on a more personal level. It will also require parents to feel adequately supported to attend. Parents, like young people, need to be able to discuss any worries they have, be trained according to the requirements of the role, have expenses reimbursed and their participation rewarded. They should be offered a debrief after each engagement event to discuss any issues which arise. Parents involved in participation have told us that sometimes they feel the support that is available to young people who participate is missing when it comes to parents and carers and this contributes to poor engagement.

Parent and carer participation can take many forms and is not limited to a formal participation group which meets regularly. As with all engagement, good strategy will recognise that there is no 'one size fits all' model. Some parents will feel more comfortable with certain activities than others and some will have more or less time to give. If their child is still unwell, it may be that they can be more involved at some points and not at all involved at others. A good participation lead can build a relationship with parents and carers so they feel comfortable being able to opt in where they want and able to discuss any worries they have.

Parents and carers can be an asset to a huge range of participation tasks including recruitment, strategy, service design, staff training and resource development. Utilising their expertise can ensure you have better engagement with other parents, reduce complaints and create services more shaped around young person and parent needs.

Support

In a situation where a young person is having difficulties with their mental health, it is experienced by the whole family, yet support is often not available to parents, siblings or other important relations. Parents have said that they would like support to be available and for it to take a systemic, family centred approach.

By the time their child reaches an initial assessment with mental health services, parents are often mentally and physically exhausted. They may have been awake looking after a young person who wants to harm themselves, or been on the receiving end of anger, frustration or violence. In many cases they will have been doing this for a long time and are wondering how much longer they can keep going for.

There may be other circumstances they have to juggle, including caring responsibilities, jobs or other children to look after. Siblings are likely to have been affected by the situation and this can add to the stress and worry parents and carers are feeling.

Many parents are concerned about stigma and ashamed that this is happening in their family. They may avoid talking about it to others, even close friends and family. This means they do not use their usual support networks and can be left feeling isolated and alone. Young people are often aware of the additional stress they are placing on their parents and this can add to the guilt and negative emotions they are feeling. Providing support to parents can also relieve some of this pressure young people place on themselves.



TOP TIP Parents have suggested it is useful to have a named person, such as a carer liaison, they know they can approach to talk about support.

There are considerable differences in the type of support offered by services. In some areas very little support is available. In other areas, carers are offered 'parenting classes' to help them think about ways to manage the situation at home. However, these can inadvertently result in them feeling they are being blamed for their child's difficulties and reinforce feelings of guilt. It is important that support takes a strengths-based approach and professionals engage on an empathetic level, understanding of what the parent is going through.



TOP TIP Many parents say they would like to be able to access peer support and talk to other parents who are, or who have been in a similar situation.



Peer support groups can be helpful for parents to understand that their feelings about their situation are not unusual, that there are other families dealing with the same issues and they are not alone. It can also be a way of swapping practical tips on what has worked for other families.

While peer support can be invaluable, it is important that it is developed thoughtfully and is well-resourced to ensure it is safe and the parents involved are well supported. Parents involved in peer support will often still be managing difficult home situations. Talking about their experiences and taking on other people's issues can become overwhelming and strong supervision and debrief practices will need to be in place.

While peer support can be invaluable, it is important that it is developed thoughtfully and is well-resourced to ensure it is safe and the parents involved are well supported

Developing parent and carer participation

“What professionals think people need and want is not necessarily what they do want and need, and the only way to understand those needs are by really listening to us. They can do that in sessions but then in focus groups, and parent groups and other methods – once they listen they can be more responsive and we can work together in partnership.”

– Amplified Parent Advisor



Involving parents and carers in service design and improvement allows them to use their experience and knowledge of the system to develop ways to better meet the needs of families. This can be beneficial anywhere in the system from prevention and early intervention through to specialist services.

Designing good participation involves working out which groups of parents and carers need to be involved in what aspects of decision-making and to what level. For some participation activities, 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.

Levels of Participation

Different parents and carers may want to have differing levels of involvement in participation. All parents should be offered the opportunity to be informed and give feedback on their experiences, while a smaller group may want to get more involved in more in-depth projects. Within participation projects, the level of involvement and decision-making parents are able to have may depend on the nature of the project they are working on, organisational policy or other external considerations.

The Ladder of Participation

The Ladder of Participation is a helpful model of understanding involvement. Used by NHS England and NHS Improvementⁱ and Young Minds, it is adapted from Arnstein's ladder of participationⁱⁱ. It describes the different ways that people can be involved and the level of influence they have. At YoungMinds we like to think of the ladder laying on its side to recognise that there is a use for each of the different levels, depending on the project, but methods toward the end of the ladder involve transferring greater levels of power and influence to the group of participants you are working with.

Informing >>>	Consulting >>>	Involving >>>	Collaborating >>>	Devolving
<ul style="list-style-type: none"> • Providing information about projects or decisions to the people they impact. • This could include posters, websites or newsletters. 	<ul style="list-style-type: none"> • Asking for feedback and using this to influence the decisions made. • This could include focus groups or experience of service questionnaires. 	<ul style="list-style-type: none"> • Ensuring consistent inclusion in decision making processes. • This could involve being on partnership boards or service evaluation groups. 	<ul style="list-style-type: none"> • Working together to identify problems, set goals and design solutions • This could include co-production, working groups or co-design. 	<ul style="list-style-type: none"> • Giving over direct power for decisions over to participants • This could include control over resources & budgets, developing resources.

“Co-production for some people might mean inviting parents to events or having people sit on boards, but for me it’s 100% equal partnership, involvement and action.”

– Wendy Minhinnett, Founder, Rollercoaster Parent Support

Dimensions of Participation

When designing participation, the level is not the only important consideration. Other aspects have been set out by Kirby et al (2003)ⁱⁱⁱ, in their list of 'dimensions of participation'. Although these have been created around children and young people's involvement they are equally applicable to parent and carer participation.

We should consider:

The focus of the 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?

The content of the decision-making – what is the scope of this decision and how much risk is associated with it? What resources are implicated in this decision?

The nature of the 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?

The frequency and duration of participation – what level of time commitment is required from the participant? How often will this take place? How does this fit with the existing commitments of the people you are hoping to get involved?

Characteristics of people involved – how do those 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.

Focus

Content

Nature

Frequency
and duration

People

Types of parent and carer participation

There is no 'one size fits all' approach to participation. Different parents and carers will have different interests, skills and time commitments. By offering a variety of ways to get involved, preferably on a project by project basis, parents can find a level of involvement that works for them.

Whichever way you involve parents and carers, it is essential that you take time to feed back to them about the influence their involvement has had. Not only does this step let participants know their input is valued, but failure to do this can reduce the likelihood of people getting involved again in the future.

Listening events and focus groups

Organising a listening event or series of focus groups is a useful way to consult parents on a specific topic or piece of work your organisation is doing, or to gain information about your service at a specific moment in time. It will usually provide rich, qualitative data which can give you good insight into the areas of your service parents feel are working well, and those that require improvement.

To get the best information from your participants, it is best to make the day engaging and interactive by using small group activities to start discussions and suggest ideas. This can help people who feel less comfortable talking in big groups to feel able to have their say. You may want to put a facilitator in each group to make notes on the discussion and make sure the conversation flows. You could use the parent user journey exercise found in the appendix as a starting point.

Listening events often sit within the 'consulting' level of the ladder of participation. It is important to be honest about how much influence parents can have and how their opinions will be used. If parents have not felt listened to prior to the event, you may find it can become the focus of a wider range of issues than what you are trying to consult on so make sure it is part of a wider strategy of getting feedback about their experiences.

Family Days

Family days are a good way to open up communication with parents and carers, as well as providing information, support and the opportunity to meet other parents and carers in a similar situation. There is flexibility to tailor their content to the needs of the cohort you have at the time and respond to any common issues that have been previously raised.

These days will require good facilitation and support from staff but can make a big difference to families' experiences of care. It can be more challenging in general mental health settings to find topics that apply to all young people, parents and carers but you may be able to find universal subjects or run specialist days for certain topics.



Family Day, The Phoenix Centre, Ida Darwin

What is it?

The Phoenix Centre is a specialist eating disorders unit for young people ages 11-17. As part of the treatment offered, the unit runs regular family days. These well-attended events serve multiple purposes including psychoeducation, peer support and feedback.

How does it work?

The day has three parts to it. It starts with a learning session from a professional on a topic related to the young person's illness. This could include body image, occupational therapy or life after discharge. In the next session young people and carers have separate sessions. Young people hear from an ex-service user while parent and carers meet with ex-parents who have had a child who has had an admission at the unit. There is an opportunity for discussion and questions.

The final session of the day involves bringing everyone together for a larger discussion. The subject is free flowing, depending on what comes up, and is facilitated by the psychologist and family therapist.

This can be very emotional, and it can be difficult for parents at the beginning of their journey to hear from families who have been on a four-year recovery journey, but overall there is a sense of hope and feedback from the event is good.

TOP TIP

Events like these are a good opportunity to give out carer surveys or hear parents' feedback about their experience of care.

How does it help families?

“Peer support is one of the reasons it works. Everyone in the room is in pretty much the same boat but at different stages of their own or their child's recovery.

The ex-service users openly talk about the ups and the downs of recovery and life after an admission and don't just portray recovery as an ideal, but parents and young people can see that there is light at the end of the tunnel.”

Bryony Dale, Head of Patient and Parent Involvement, Ida Darwin



Participation and Support Groups



The most common method that services use to develop their parent and carer participation is by setting up a parent and carer group. Groups can be focused on support, psychoeducation or participation, or include a combination of each of these elements.

Setting up a successful group can be challenging and it may take some time to establish a regular group of attendees. Think about how the opportunity is communicated to potential members and the perceived relevance to the people you want to engage. What benefit do you want parents and carers to get from attending? What do they want to get out of it? Developing a group in partnership with a parent or carer is one way to improve its relevance to your audience.

Consider the time and location your group takes place and how this fits with other responsibilities your parents and carers have. It might be hard to find a time that works for everyone so you could vary when the group meets to allow the maximum number of people to attend. Often the best day for parents and carers to meet might be a Saturday.

Being part of a parent and carer group, even if it is focused on participation, can bring up strong emotions, especially if parents are still in the process of trying to look after an unwell child or if this is the first time they have been able to express to services, or their peers, how difficult their journey has been. As part of setting up a group, it is vital that you think about the support arrangements you put in place to ensure parents can participate in a way that feels safe. Starting and ending each session with a check in, providing a space where parents go if they need to take some time out and providing opportunities for support after a session are all arrangements you could put in place to create a supportive space to participate. The facilitator(s) of the session should also receive good supervision as they can end up absorbing complex emotions or dynamics present in the group.

It is also a good idea to start by creating a group agreement about how the group will operate. This can include basic rules around confidentiality, respecting others' contributions and giving everyone space to speak, but could also include ways to ensure that the atmosphere of the group remains positive, focused and supportive. This can be returned each session to remind participants of what has been agreed and to check it still feels relevant and appropriate to the group.

In partnership with Tees, Esk and Wear Valleys Foundation NHS Trust

Rollercoaster Parent Support

What is it?

Rollercoaster Parent Support was started five years ago by a parent, Wendy Minhinnett. When her daughter became unwell she saw a huge gap in the support available to parents and carers. Now an award-winning project working with parents and families across the region, its focus has grown to a community-based peer support model, delivered in partnership with her local Children and Young People's Mental Health Service (CYP MHS).

How does it work?

The Rollercoaster Parent Support model has a number of elements to it. As well as running a face-to-face support group, there is digital support in the form of a Facebook group and training for parents about mental health issues. The organisation also does advisory work on the parent and carer experience, which feeds in to service development, and provides workforce training to NHS staff.

Wendy says that it is the combination of personal experience and professional expertise that makes the group a success.

"My initial expertise was personal experience as a parent. I couldn't stand there and run this group if I

hadn't been through it myself. A professional without experience couldn't run this without a parent. The partnership with CYP MHS and other agencies is crucial in order to offer support"

The other key element is peer support:

"It's not just about talking, it's about action. We may have similar problems, but what can we actually do about it? One parent might have an issue, but another parent has been there and already solved it. The peer support is more significant than anything."

What barriers were there to setting it up?

"What made us wobble at first was that nobody came for the first three months. We started to doubt if it was needed. Then people came through the door, and so many of them said that it had been fear of the stigma around mental health that had stopped them showing up sooner. The Facebook group is important with that; some people read others' posts for months at a time before they call up and ask for help.

Keep going, don't be disheartened when people don't walk through the door."

Read more about Wendy's participation journey on page 38

Rollercoaster Parent Support Model County Durham

Supporting parents to support children and young people with emotional and mental health issues

Support Groups

- 2 per month (evening and daytime)
- CAHMS Support

Advisory Work

- Parent voice
- Service developments and improvements

Digital Support

- E-network
- Facebook-closed and open group
- Advice, information and sign-posting

Training

- Parent training around mental health issues
- Peer support training
- Signposting to E-learning
- Workforce training

Staff recruitment and training

Involving parents and carers in staff recruitment and training can be a powerful way to increase their voice within a service. Results from the Amplified participation audits carried out in organisations around England indicate that young people are more likely to be involved in these areas than parents and carers, despite both groups having important perspectives to contribute.

It is essential that parents and carers are appropriately prepared for the role that they take on to ensure their participation is effective and meaningful. Think about how much time you need to do this and how much time participants have to give to the process. If participants feel underprepared they may not want to be involved again in the future, but if you support them to develop the skills they need for the role, they are more likely to continue to be an asset to your organisation.

Some parents and carers may have professional experience of being part of an interview panel or facilitating events, but it should not be assumed that this is the case. Support them to understand the requirements of the role. Ask participants about the skills they already have and those they would like to develop. Learning new skills and taking on these roles can benefit participants' confidence, as well as creating positive action from a difficult experience.

Creating genuine participation can be challenging and it is important to acknowledge that there is a power imbalance inherent in the relationship. Parents and carers may previously have felt powerless when dealing with services and it is important that they know their contribution is meaningful. Building trust between parents and carers and the service is the foundation for genuine participation and the sharing of power.



Recruitment

Empowering both young people and parents and carers to have an influence over employment indicates a commitment to developing services designed around the needs of the people who use them. Participants bring added value to the recruitment process as they will often notice different aspects of a candidate to professionals, providing a more complete view of their suitability for the role.

There can be variation in how participants are involved in the recruitment process. Some services create a separate panel in addition to the panel of professionals but it is important to make clear how this additional information will be considered alongside professionals' feedback or it can feel tokenistic. Having participants on the main interview panel alongside professionals means they are involved in all aspects of the process and allows professionals to see how candidates engage with participants.

Parents and carers could be involved in other aspects of the recruitment process including shortlisting candidates and deciding the most important traits to be considered as part of the person specification. They could also provide feedback on the recruitment process itself to ensure that their participation is meaningful and they feel they have been listened to.

Training

Parent and carer participation in staff training shapes the organisational approach to parents and carers overall. Involvement can happen at a number of levels, depending on the role participants feel comfortable with. Some parents may feel more comfortable assessing the existing training content and making suggestions about how it could be improved. Others may want to create resources about the parent and carer journey which can be used by training facilitators to illustrate the lived experience of those who interact with the service.

Parents and carers may want to get involved in the direct facilitation of staff training. This can be a powerful way to support staff to understand the difficulties parents face in the journey of getting help for their child. Not every participant will want to be involved in this way but, with the right support, any parent or carer can develop the skills to tell their story to influence change. Some may feel confident enough to co-develop and co-facilitate the whole training course, agreeing the content and delivery alongside staff.

Whichever way parents and carers are involved in training, it is important that they are fully supported. While being involved in this way can be empowering and create change, it can also be re-traumatising, bringing up emotionally charged memories and difficult feelings. It is essential that the participant is in the right place in their journey to tell their story and that they are prepared beforehand and debriefed afterwards to ensure their participation is a safe and positive experience.

In partnership with North West CYP IAPT Learning Collaborative

CASE STUDY: Cme in the Community

About

Cme in the Community and North West CYP IAPT had been working together to improve participation but had identified that providers were finding parent and carer involvement challenging. They applied to Amplified with the aim of building parent and carer participation structures across services in the area.



What happened?

The network started by mapping out existing parent and carer participation in the organisation. They looked at where current involvement opportunities sat against the ladder of participation and dimensions of participation. Using the standards set out in the Amplified Parent and Carer Participation Audit, they identified areas of good practice and areas where there was room for improvement.

They ran an insights session for parents and carers to hear their experiences of accessing help for their child, and gathered their views about how they would ideally like services to engage with them at each stage of the journey through treatment.

These insights were used to create a training course, Getting Started with Parent and Carer Participation within your Mental Health Service. The course was designed to be co-delivered by parents and carers to participation leads for services in the area.



Co-producing resources

The importance of parents being able to access good quality information about what is happening to their child and how to access help has already been highlighted. One way to ensure that this information is clear and relevant to its audience is to involve parent and carers in creating it.

Parents and carers who have experienced the journey through young people's mental health service will have the best idea of the information other parents will be looking for at each stage. It could take the form of written information, development of a website or online resource or a social media campaign to help engage others on their experiences and offer support and guidance. Involving parents and carers in producing it gives authenticity to what is said.

This also applies to the production of parent and carer friendly versions of policy documents, such as confidentiality or the complaints process. These documents are often written from a service point of view and can feel dense and inaccessible to those who need to use them. Working with parents to create a version that explains what they need to know in clear, simple format allows everyone to access the relevant information and hold services to account where necessary.

The amount that parents want to be involved in this may vary but co-production in its truest sense means parents and carers being involved as equals throughout the process, from deciding what the content or words should be, through to the look and feel of a resource or communication. This allows parent and carers ownership of something which captures the complexity of their views, experiences and concerns in a way that allows this to be communicated to a wider audience.



Commissioning and service design

Involving parents and carers in the commissioning and design of services can provide valuable insights into how well services are working. Talking to parents about how their help seeking journey could have been easier can identify gaps in provision or barriers to young people accessing support. It can highlight areas which need improvement and this can then be used to inform service specifications and care pathways.

The lived experience of parents can also be a powerful tool for change. It can be used to make the case for new initiatives and influence strategic planning. Hearing a different perspective on the strengths and weaknesses of the current system can generate new ideas and challenge the status quo.

Parents and carers can be practically involved in shaping new services and testing out the responses that parents will receive from professionals. Shaping services around the needs of young people and parents and carers from the outset means services are designed around the needs of the people who are going to use them. Commissioners can also support parent and carer participation by ensuring it is written into contracts with provider organisations when they are commissioned, or recommissioned.



Evaluation

Parents and carers can be involved in evaluating services through the completion of surveys or attending feedback events, but they can also take a larger role in shaping organisations' evaluation processes as a part of a monitoring and evaluation group.

Involving parents in evaluation from the beginning means they can advise on all areas of the process. This could mean ensuring services are measuring things that are relevant to those who use them, employing tools which are appropriate to the group they are being applied to, validating findings and assumptions or bringing a different perspective to the process that generates ideas that professionals alone may have missed. They may also be better placed to advise on how to approach other parents and carers and involve them in providing feedback on their experiences.



Governance



NHS England and NHS Improvement guidance^{iv} is that there should be participation present at all levels of the system, and this includes governance. NHS Trustee Boards function as “a system of accountability to citizens, service users, stakeholders and the wider community”^v and therefore there should be transparency around the way they operate and how the groups they represent contribute to the decision making process.

Parents and carers who are involved in the governance process can help shape the vision of the organisation, develop strategy and influence leadership. They can also ensure the parent and carer perspective is heard, constructively challenge assumptions and act as a critical friend.

Parents and carers can contribute to a governance board through a number of different roles. The main differences between the roles are the level of influence that representatives are able to have, and the legal responsibility they assume.

- **Full trustees** – have the same decision making power and legal responsibilities as other members. Parents and carers are in a slightly different position to young people in this instance, as only people over the age of 18 can become full trustees.
- **Co-opted board members** – can attend the full board meeting and contribute to discussions but are unable to vote.
- **Advisors** – can attend some parts of the board meeting and contribute to discussions
- **Sub group** – meets separately to discuss items on the board agenda then a representative attends the board to feedback on the discussion.

If we look at these roles using the ladder of participation, becoming a full trustee is a devolved position where parents and carers are placed as equals with other board members, while creating a subgroup is a consultative role which means the group’s voice may be heard but there is no guarantee of the influence it will have. Only full trustees take on legal responsibilities.

Parents and carers who take on these roles should receive a full induction and training on the role they have taken on and the way the systems they are working within operate. It is also very important for professionals to consider how much jargon is used within these meetings. Many NHS initiatives and teams are referred to by acronyms which can be alienating to anyone from outside the system who is trying to participate. Consider how to make these meetings accessible, through use of a pre-meeting to answer any questions or by providing a glossary of terms which participants can refer to.

CASE STUDY: Norfolk and Suffolk NHS Foundation Trust

About

Norfolk and Suffolk NHS Foundation Trust applied to be a trailblazer after they identified that parent and carer evaluation was an area that the organisation could improve on.

“We pride ourselves on being a learning organization and recognise that to transform care we need to listen to consumers... We see the role of parents/carers as ‘critical friends’/ advisors within our service line as essential.”

What happened?

“Our first objective was to listen to the views of parent/carers about how we could better support them, our CYP and importantly how we could involve them going forwards in our service transformation / improvements. This was the most important phase and really listening to their views felt important.

We did this through holding 2 listening events across Norfolk and also surveying parents/carers (in one area). In addition, we included our parent/ carer representative throughout and she has been so valuable in steering this and using her own experience to inform our themes and recommendations.

We used the themes across these activities to start thinking about a set of 10 clear recommendations to present to the Governance Committee and senior leadership team.”

Developing a Parent and Carer Participation Strategy

If you want to increase your parents and carer participation and make it purposeful, a good way to start is by creating a parent and carer participation strategy. This is a substantial piece of work, but doing it will help you think about what you want your participation to achieve and the steps you need to take to get there.

This list is intended to help you as an organisation to develop a participation strategy, based on current practice from YoungMinds. It will help you to reflect on the current levels of participation in your service and set your organisational goals and aspirations for the future.

Define your organisational objectives

- What does your organisation want to achieve?
- How is parent and carer participation going to support these objectives?
- How is this supported by many local and national policy documents?

Map what is already there

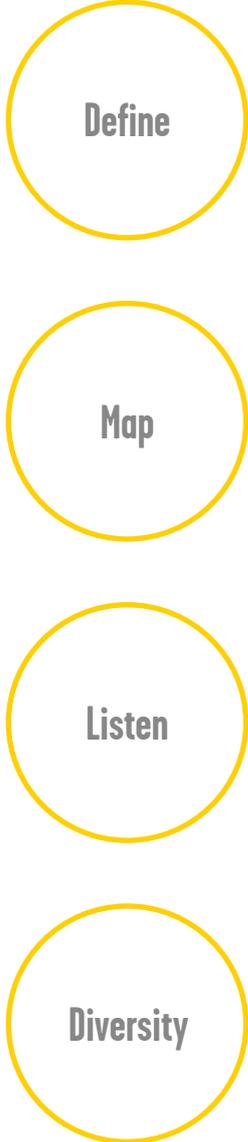
- Where is parent and carer participation taking place in your organisation?
- What is strong about your current approach?
- Where opportunities are there to build it further?

Start with listening events

- What do parents think about the current service?
- What do they think are the priorities for improvement?
- How could these areas be improved?

Think about diversity

- Is your participation representative of the demographics of your community?
- Which groups are currently not being heard?
- How are you going to engage with those groups?



Define

Map

Listen

Diversity



Develop your activities

- How are you going to ensure parent and carer voices are heard within the organisation?
- How are you going to support participation in leadership?
- How are you going to support participation in service delivery?



Plan system support

- What funding is available to support parent participation? Is this a protected budget?
- Which staff are going to lead on parent and carer participation?
- How are you going to ensure parent and carer participation is supported by the wider system, from clinical and support staff through to senior management?



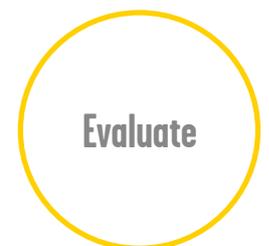
Plan support for participants

- How are you going to ensure participation is meaningful for participants?
- What measures are you going to take to make participation accessible to all?
- What will parents and carers need to ensure their knowledge, skills and emotional support needs are met?



Evaluation

- How are you going to monitor that the strategy is being met?
- How will you assess the impact of your participation activities?
- When will the strategy be reviewed?



Senior leadership support

One of the key factors for success when developing and implementing a participation strategy is the support of the senior leadership of an organisation.

Our Amplified Insights Survey found that professionals feel that their organisations don't always have commitment from leadership to enable good quality participation of young people and parents and carers.

The same survey found that 55 per cent of parents said they would be interested in meeting with senior leaders within the service, to share their views directly.

It is essential that leaders really understand the value that parents and carers' experiences can bring to improving services, rather than seeing it as a tick box or something that sits aside from the day-to-day running of a service.

Do not underestimate the impact being visible and engaged in parents and carers' views has on the experience and journey of supporting their child.

There are a number of ways that senior leaders can get involved in participation with parents. This could include attending a number of parent participation sessions, groups or family days throughout the year, inviting parents to speak at board meetings about their experiences, to inviting parents and carers to sit on central governance groups.

Engaging Participants

Professionals often tell us that they find it difficult to get parents and carers involved in participation. The reasons for this can be varied and may be influenced by the type of service, how much contact parents have with staff or how unwell their child is.



You might find that there are one or two parents who are enthusiastic about getting involved. If this is the case, encourage this. You could think of smaller projects or 'quick wins' and get them involved in these. Once you can show that parent and carer participation is leading to meaningful changes, the success of this can help engage other participants. Parents and carers who engage early may also be able to develop ideas about how to appeal to their peers.

Every interaction with parents and carers is an informal opportunity to engage so when you get the chance, ask them about their experience. This can help create a culture of listening and bring participation activities to their attention. A big challenge to engagement can be making sure parents are aware of the opportunities being offered. A poster on the wall of a waiting room is a good first step but may require more active follow up to get people involved. Information about participation sent out with your pre-appointment letters can also be mentioned in the appointment, so it can be discussed further and gives parents and carers the opportunity to ask any questions they may have. Advertising opportunities on your website or social media channels may actually be more likely to attract parents than young people, as these are common locations parents are likely to look for information to help their child.



Every interaction with parents and carers is an informal opportunity to engage so when you get the chance, ask them about their experience

It is helpful to think about parents and carers' motivation to get involved. What do they want to get out of it? Initially parents may be looking for information and support, but once they are receiving this and you have built a relationship with them, suggesting they get involved in participation activities could be the next step.

For many the feeling of having made a difference is the biggest motivation. When families have had difficult experiences accessing support, they want to make sure the same does not happen to anyone else and turn their negative experience into a positive. For this to be the case, participants need to feel listened to and they need to see that organisations are responding to what they say. Any consultation with parents and carers must be followed up by feedback about how their involvement has been used to create change in order for it to feel meaningful.

Think about the activity you are asking them to take part in. Could it be perceived as tokenistic or feel like a 'tick box' exercise to those who are involved? Consider the ladder of participation and how much influence participants really have. If there are things that cannot be changed, then be honest about this.

When young people do become seriously ill, a parent or carer sometimes needs to leave their job to care for their child. This significant change to their lives can be hard to adjust to and as the young person in question gets better, parents are often unsure what to do next. Participation can be a way for them to use the knowledge and experience they have gained to help other people in a similar situation. For parents who are fully supported and upskilled to be able to speak up and make a genuine difference within services, this can be a significant achievement. It is also important that participants are adequately rewarded for their input, including payment for their time where possible, in recognition of the difference they are making to the organisation.

Often opportunities for participation within young people's mental health services take place during the week and rely on parents with jobs being able to leave work in order to attend them. This creates a barrier to the participation of parents with insecure or inflexible employment. Much of the time this means those from lower socio-economic backgrounds, resulting in these voices often being excluded from the conversation. To use participation to improve the experience of getting help for all families, you need to hear from the widest range of parents and carers possible.



It is helpful to think about parents and carers' motivation to get involved.

What do they want to get out of it?

Representation in Parent and Carer Participation

When parent and carer participation structures are being established, you need to consider whether the parents that are involved are representative of your local population. In many cases those who participate come from a similar background and, while the experiences of all who participate are important, it is also vital to consider which voices aren't being heard.



Achieving representative participation is likely to be challenging and requires more proactive engagement strategies. The 'usual suspects' are more likely to feel confident expressing their opinion and getting their voice heard but this can mean they are over represented in participation. Other parents may see a poster advertising a parent participation opportunity and assume that it is not them that services want to hear from.

In general, young people from ethnic minorities are under-represented in mental health services. Research by Mind has found that 1 in 4 people from Black and Minority Ethnic (BAME) backgrounds do not share their mental health experiences and young people from these communities are more likely to reach a crisis point before they come into contact with services^{vi}. These young people miss out on opportunities for early intervention when their mental health begins to suffer but later in life are over-represented in admission and detention rates among adults^{vii}. Young people from a BAME background are most likely to come in to contact with mental health services through a criminal justice route^{viii}, although even there, they are less likely to be identified as needing mental health support^{ix}.



Research by Mind has found that 1 in 4 people from Black and Minority Ethnic (BAME) backgrounds do not share their mental health experiences

There are complex reasons for this. Stigma and negative cultural beliefs around mental health are a factor in some communities. There may be less awareness of mental health issues, social networks may be less open to discussing mental health and perceptions of gender or accepted ways of coping can also reduce the likelihood of seeking help. This means parents and carers of young people with mental health problems are likely to feel isolated with their experience of caring for their child with mental health problems and may be even more in need of support from other parents in a similar situation.

Young people identified that a lack of understanding about the culture of people asking for help was a significant factor that would prevent them from accessing sources of support. Commissioning and improving services with young people and families from BAME backgrounds can increase our understanding of the experience of these families when accessing mental health support and result in services which meet the needs of the community, in turn leading to better outcomes for young people. Reaching out and engaging parents and carers from a BAME background in support and participation opportunities has the potential to have a significant on the parents themselves and the young people who use the service. It also means that parents and carers who participate and as a result increase their knowledge and understanding of mental health and mental health services may end up acting as a champion within their communities, increasing the benefits of their involvement.

However, parents and carers will need to feel that participation opportunities are aimed at them and that their voice will be heard. When they walk into a room, they need to feel that they will be listened to and understood.



Young people identified that a lack of understanding about the culture of people asking for help was a significant factor that would prevent them from accessing sources of support

Conclusion

Involving parents and carers in the care and development of young people's mental health services can provide an invaluable resource for your organisation and offer them support through one of the most difficult experiences of their lives.

This toolkit has provided insights into the experience of parents and carers who come into contact with services, based on what they have told us they need to help them support their child to the best of their ability. The relationship between parents and carers and mental health services can be fraught but approaching each interaction with empathy and understanding has the potential to create more positive engagement and better outcomes for young people.

There are many ways that services can involve parents and carers in the way they run and some ideas and practical examples of how to do this have been provided, along with things to consider when developing your parent and carer participation strategy. Using these we hope that services can take the next steps to ensure parent and carer participation is not seen as an add on activity but a central feature in the way they operate.

Reflections on parent and carer participation with Wendy Minhinnett

Founder, Rollercoaster Parent Support

Rollercoaster Parent Support (@RollercoasterPS) was a project begun five years ago by a local parent, Wendy Minhinnett. Now an award-winning project working with parents and families across the region, its focus has grown to a community-based peer support model, delivered in partnership with Children and Young People's Mental Health Services (CYP MHS).



Tell us about what motivated this project / campaign

My daughter being unwell – I'd worked in family support and community support for a number of years and saw a huge gap. My professional background told me that this should be a partnership with CYP MHS. That was our vision from the beginning, that this should be a partnership that was parent-led, professionally supported. We still stand by this ethos.

One of the things about the group – it's not just about talking, it's about action. We may have similar problems, but what can we actually do about it? Having a CYP MHS worker in the room and links with other services addresses that, but so does peer to peer support. One parent might have an issue, but another parent has been there and already solved it. The peer support is more significant than anything.

What were key barriers to it being successful?

What made us wobble at first was that nobody came for the first three months. We started to doubt if it was needed, or was it just me as a lonely parent with all these issues? Then people came through the door, and so many of them said that it had been fear of the stigma around mental health that had stopped them showing up sooner. I hadn't realised how nervous people were to come through the door. Parents told me "It took us months to build up to come, I nearly drove out of the carpark". I've had parents tell me they walked past the door five times before they came in.

The Facebook group is important with that; some people read others' posts for months at a time before

they call up and ask for help. I got a call from someone whose partner wouldn't let them tell anyone about their child's mental health. Because we're all so involved in mental health we sometimes forget that there's a massive stigma out there. That continues to be a barrier.

The first two years we did this voluntarily. It took so much time to do it well, and that impacted the quality of everything. Getting funded removed that barrier and gave us the time to do it properly. There are so many things that need to be led and developed. Now five years in we have a model to work to.

What expertise or skills did you have? What did you need to bring in from outside? Whose buy-in was important and how was it demonstrated?

My initial expertise was personal experience as a parent – it gives you credibility. I couldn't stand there and run this group if I hadn't been through it myself. A professional without experience couldn't run this without a parent. But professional experience isn't enough alone to link people to effective support – the partnership with mental health services and other agencies is crucial in order to offer support.

We have speakers come along every month from different services – benefits, carers, headteachers. Having key issues addressed as a whole system partnership makes it work. The other crucial buy-in was our local transformation plan – we were part of the conversations, and seeded the issues that came straight from parents over two years. Their views inform the core strategic view for the area and help address real gaps.

What did you learn along the journey about co-production and participation?

In a nutshell? It's the way forward, it is what we have got to do. Co-production for some people might mean inviting parents to events or having people sit on boards, but for me it's 100% equal partnership, involvement and action. You've got to see the things that are actually happening – recognising the contribution people can make in every step along the way.

So many people want to come and “consult” – they come, they talk, they write whatever plan or document they want to. What they often fail to do is come back and feed back to our parents. I've stopped inviting people that do that!

What are your Top Tips to other organisations wanting to develop a participation project with a group like this?

- **Do it** – don't just think about it
- **Listen.** My ultimate top tip. Listen to what parents are saying and act on what they want – every local area will be different, so don't assume it's all been said before.
- **Keep going,** don't be disheartened when people don't walk through the door.
- **One size doesn't fit all** – have different threads to what you offer. Facebook, face-to-face groups, involvement and advisory opportunities.
- **Start small, think big**– parents and families really are part of the solution to improving outcomes for children and young people.

We are all in this together and our group motto “We get strong together and do the best we can” applies to organisations as well as families.

What, if any, additional safeguarding considerations were there?

Right from the offset in our ethos we always mentioned the boundaries around confidentiality. There's sometimes a fear that it'll put people off talking, but it helps people stay safe. We've had to get people additional support, and signpost people to the right help, but the ethos has meant that we've avoided

having to make safeguarding referrals – honesty is crucial too.

From a personal point of view, clinical supervision is crucial to support this, because you can't help but take on some of the issues as if they were your own. The crisis team and the rest of the team at Tees, Esk and Wear Valley Foundation Trust have been essential – to have that as a small voluntary sector organisation has kept us safe.

What impact have you had? What impact do you hope to have?

The amount of people that are coming through the door and keep coming back, or going on to help others, tells us that we're helping people when things are at their worst, and then helping people move on.

The change in people you see coming from someone who's desperate, who can't see the wood for the trees, getting to a stage where they can offer peer support, advice and information, is a sign that we're making a difference. We get emails from people who've never attended our groups but accessed our online information saying how much we've helped; there's a huge variety of outcomes because of how multifaceted the programme we offer is. This year will see Rollercoaster formally evaluated with a partnership between The Charlie Waller Memorial Trust, Association of Young People's Health and Northumbria University. I hope this will help really show the difference supporting and involving families can make

What comes next for your project?

Rollercoaster is now a project embedded into our local children, young people and mental health pathway, we have core funding from the Clinical Commissioning Group which is fantastic. Next steps are developing and piloting parent peer support training and embedding these roles into the local systems. Rollercoaster founder is also working with the Charlie Waller Memorial Trust to help develop parent support in other areas, so help is available if you would like to set up parent support. It's fantastic to see and be part of the growing number of parent support projects around the country.

“If you are thinking about developing parent support-just do it. There's plenty of practice to learn from and no need to reinvent the wheel!”

Parent and Carer Journey Insights Worksheet

What actions did you take?

What support did your child receive?

What support did you receive?

Positive factors

Negative factors

Prior to referral					
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Referral					
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Assessment					
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Getting support					
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Preparing to move on					
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Endnotes

- i NHS England (2013) 'Transforming Participation in Health and Care: 'The NHS Belongs to Us All'
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- ix Lammy, (2017). The Lammy Review. An independent review into the treatment of, and outcomes for, Black, Asian and Minority Ethnic individuals in the Criminal Justice System







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.



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