

Barriers to Participation: A Transforming Care Partners Resource



Children and young people's participation

All children and young people have the right to take part in making decisions that affect them, regardless of their age or support needs, in line with their evolving capacities. This right is enshrined in Article 12 of the Convention on the Rights of the Child (1989), and the importance of this right for disabled children and young people is re-emphasised in Article 3 of the Convention on the Rights of Persons with Disabilities (2006).

The specific role that voice has to play in UK health and care contexts is addressed in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 Regulation 17,¹ and the Care Quality Commission (Registration) Regulations 2009.²

However, there are many barriers to disabled children and young people participating in meaningful decision-making. This resource will identify some of the common barriers to participation that children and young people have identified specifically in the context of their health, care and education services, and propose some solutions.

About this resource

This resource refers to 'formal' and 'informal' participation opportunities. 'Formal' opportunities are planned opportunities where children and young people are invited to share their views and opinions. This may include participation groups or regular review procedures, delivered using activities and engagement methods appropriate for the children and young people involved. 'Informal' opportunities are unscheduled opportunities for children and young people to be heard, such as a young person holding a casual conversation with a member of staff or spontaneously drawing a picture of the things that make them happy on their ward.

Although many of the children and young people who have contributed to this resource are speaking about their participation at the individual level, the issues that they raise are equally applicable at the operational and strategic levels.



¹ <https://www.legislation.gov.uk/ukxi/2010/781/regulation/17/made>

² http://www.cqc.org.uk/sites/default/files/2009_3112s-care-quality-commission-regulations-2009.pdf

The Making Participation Work programme, funded by the Department for Education and implemented by the Council for Disabled Children and KIDS, has produced a range of resources to support the participation of disabled children and young people with SEND in all contexts. They can be used in parallel with this resource to strengthen participation practices, including:

- [Factsheet #1: Methods and Levels of Participation](#)
- [Factsheet #4: Barriers to Participation](#)
- Degrees of Participation³



³ based on a theory proposed by Treseder, Phil (1997) Empowering Children and Young People: Promoting Involvement in Decision Making, Children's Rights Office & Save the Children.

Inadequate opportunities to participate

In order for children and young people to have a meaningful role in decision-making, they must be presented with opportunities to share their thoughts and opinions. However, children and young people have said that these opportunities are not always offered, or are not perceived as being valuable.

Barriers	Solutions
<p>Opportunities for children and young people's participation are (or are perceived as) limited, low priority or an afterthought.</p> <p>"There was no consultation on medicine changes, I was just told I need to take it. Even if I don't like it or I get a bad reaction."</p> <p>"I wasn't really [given opportunities to speak]. At the end of the meeting they said "Is there anything that you've got to say?"</p> <p>Opportunities for children and young people's participation are (or are perceived as) tokenistic, or children and young people feel their views are misrepresented.</p> <p>"I was there but whenever I spoke people just took down notes. I don't really think they did anything with those notes."</p> <p>"They phrase it like you do have a decision but really you don't."</p> <p>"Whenever I'd make a decision it was almost like the staff would overrule me and make their own decision on me."</p>	<p>All opportunities:</p> <p>Acknowledge and respect that children and young people deserve a meaningful role in decisions regarding their health and care.</p> <p>Ensure children and young people are made aware that it is their right to participate and be included in decision-making at all levels.</p> <p>Equip medical and care professionals and support staff with the knowledge, tools and skills to promote and support participation.</p> <p>Formal opportunities:</p> <p>Manage expectations by explaining any obligations or limitations before inviting children and young people to express their preferences.</p> <p>Communicate with children and young people about decisions made, how their input has been taken into consideration, and how they can give feedback on the decision-making process.</p> <p>Informal opportunities:</p> <p>"[Professionals must be] open to listen and learn."</p> <p>"[Professionals] need to encourage more general discussion, [so children and young people are] allowed to approach [them and ask] questions [or have a] conversation."</p>

Choices are made within a very limited range, which is determined by the health setting and available resources.

"There was no counselling on the ward and the activities didn't help me. There was no purpose to get up in the morning. Music therapy would have been helpful to me, but this wasn't offered."

"I was very close to being put in a young person's prison. Young offenders with mental health support... highly inappropriate [for me]."

All opportunities:

Manage children and young people's expectations regarding what is feasible early on in the decision-making process. However, do not use this as a justification not to seriously consider young people's views and explore the suggestions they make.

"Be realistic, be honest, because people could get their hopes up."

Gatekeepers make it difficult for children and young people to access formal participation opportunities.

"There are so many gatekeepers before the young people even get to say if they want to join in with the participation work."

The nature of children's relationships with health services can create obstacles to children and young people's participation.

"At some point [the participating children and young people] would leave the group, due to being discharged from hospital, and it felt like there were even more barriers to keeping them linked into the work once they were discharged than there had been getting in to talk to them in the first place."

Formal opportunities:

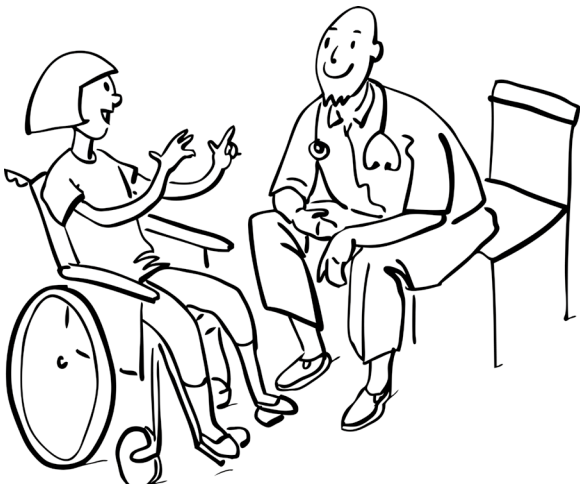
Build positive relationships with gatekeepers so that they understand the importance and value of supporting all children and young people to take a meaningful role in making decisions about their healthcare.

Remember that young people do not have to be in formal meetings, they can input in other ways, for example:

- Via clubs or schools
- By sending in videos or photos
- Via social media

Children and young people's personal experience

A child or young person's own background, preferences and previous experience of sharing their views can impact on their willingness and ability to engage in activities around decision-making.

Barriers	Solutions
<p>A lack of choice regarding the adults who support children and young people to engage in participation activities.</p> <p>"As my younger self, I wouldn't have really liked [particular members of staff] there but as I am now, I probably would."</p> 	<p>All opportunities:</p> <p>Explore alternative ways for children and young people to share their views with other professionals, such as videos, pictures and audio recordings so they do not have to be present at formal meetings.</p> <p>Formal opportunities:</p> <p>Include children and young people in recruitment processes for staff responsible for participation.</p> <p>"Young people and/ or children interviewing staff."</p> <p>Informal opportunities:</p> <p>Enable children and young people to identify which professionals they would like to support them in decision-making.</p> <p>"Ask if there's any member of staff that they feel extremely close to... Well, a lot of my key workers I was very close to. I was, had a very professional friendship with them. [I would like them to] sit down and speak to me, talk to me about all the options rather than just sending me away without the information."</p>
<p>Relationships between medical professionals and children and young people are poor and/or impersonal, meaning that children and young people feel uncomfortable or unable to voice their opinions.</p>	<p>All opportunities:</p> <p>Build relationships with children and young people so they feel supported and comfortable.</p>

<p>"I feel like AMHS treats the condition, not the person."</p> <p>"[I was] treated like a machine."</p> <p>"Being asked questions by people who were essentially strangers to them did not give [children and young people] any desire [to participate] or enable them to find their voice."</p>	<p>Formal opportunities:</p> <p>"Working with hope - have a positive attitude."</p> <p>Ensure children and young people have an opportunity to input into which environment, delivery methods and support they need to be able to fully engage.</p> <p>Create a space where children and young people feel secure to share their views. Make it an adult-free zone (apart from the facilitator) if need be.</p> <p>Make meetings less formal, with an element of fun.</p> <p>Consider sessions co-facilitated by young people with SEND, as these are a good way of building trust and rapport, making topics relevant, encouraging sharing and making the sessions appealing.</p> <p>Ensure the staff responsible for formal participation opportunities have the necessary skills to build children and young people's confidence and soft skills in sharing their thoughts and opinions.</p> <p>Informal opportunities:</p> <p>Establish processes to feed informal participation opportunities into decision-making at all levels.</p>
<p>Negative experiences in other contexts impact on children and young people's attitude towards their own voice and decision-making opportunities.</p>	<p>All opportunities:</p> <p>Ensure children and young people are aware of their right to participate in decisions made about their health.</p> <p>Ensure that children and young people are aware of the processes by which their voices are heard and taken into account at each level.</p> <p>Share good quality feedback with children and young people on reasons behind decisions that have been made at each level and how children and young people's voices have been included.</p>

<p>"I was just so sick and tired of social services pushing me around, not letting me have my say or the schools not letting me have my say."</p> <p>CYP's broader emotional state impacts on willingness/ ability to participate.</p> <p>"I just didn't feel wanted."</p>	<p>Formal opportunities:</p> <p>Ensure children and young people have an opportunity to input into which environment, delivery methods and support they need to be able to fully engage.</p> <p>Take children and young people's experiences and backgrounds into account, and arrange participation opportunities sensitively.</p> <p>Informal opportunities:</p> <p>Develop a listening culture in which all staff are receptive to children and young people sharing their views informally, and are able to respond.</p>
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Staff knowledge and understanding

Children and young people's ability to influence decisions made about their healthcare relies heavily on the supporting professionals' knowledge-base and ability to act on children and young people's input.

Barriers	Solutions
<p>Professionals' pre-conceptions of conditions influence the options that are made available to children and young people.</p> <p>"Young people should have physical and sexual health examinations more frequently – it seems like health services are only concerned with mental health support for children and young people with autism."</p>	<p>All opportunities:</p> <p>Listen actively to children and young people's ideas and concerns.</p> <p>Ensure that children and young people's views are given due weight in line with their evolving capacities.</p> <p>Share feedback and learning from children and young people with other relevant stakeholders.</p> <p>Formal opportunities:</p> <p>Place participation opportunities at the centre of children and young people's services, and ensure staff from different departments are aware of them.</p>

<p>Staff knowledge-base or the setting they work in impacts on how professionals respond to children and young people's input and the range of options made available to those</p> <p>Staff lack the full information required to support CYP decision-making.</p> <p>"Even medical staff don't know about services, for example A&E staff. How are we supposed to know about them if professionals don't?!"</p> <p>"If [a medical professional] can't explain it, they should tell the young person "I'm sorry, but I don't understand. I'll get someone who does."</p>	<p>Ensure a wide range of voices are included in formal participation opportunities.</p> <p>Provide children and young people with opportunities to identify pathways and gaps between services, and strengthen these where necessary.</p> <p>Informal opportunities:</p> <p>"Everyone with autism is an individual and has individual needs. Don't put people in groups – we are all individual in terms of emotional, social and physical needs."</p> <p>"[A good medical professional] accepts whatever I came in with, I could be open and not think I needed to hide."</p>
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Children and young people have limited access to information

In order to make informed decisions, children and young people need access to all the relevant information and to fully understand the implications of their options. Often children and young people feel uninformed or do not fully understand the information they are given.

Barriers	Solutions
<p>Professionals use complex language or jargon.</p> <p>"[I was] asked about my 'level' – I never knew what this was and it made me feel confused."</p> <p>Professionals use communication styles which are not well suited to the children and young people concerned.</p>	<p>All opportunities:</p> <p>Consider language and communication methods carefully. Avoid jargon, and use Easy Read and alternative communication methods such as signing, drawing or Talking Mats when appropriate.</p> <p>"Pictures help you to focus on your work and to relax your mind, so you don't think about too much."</p>



Be aware of the children and young people's non-verbal communication patterns, as different children and young people display their emotions in different ways. This includes body language, social and emotional engagement, and behaviour that challenges. Seek support from an adult supporter who knows the child/ young person well if necessary.

Formal opportunities:

Give children and young people an idea of the questions or topics they will be thinking about in advance so they can consider their responses without undue pressure.

Invite children and young people to choose how they want to communicate. They may prefer to use film, poetry or song to communicate, either in person or by sharing a recording.

Informal opportunities:

Ensure that staff recognise that all feedback from children is valuable including alternative forms of communication, and are alert to when a child or young person are offering feedback informally.

Children and young people lack the full information to make informed choices and/ or identify services to support them.

"Doctors didn't talk to us about the side effects of the medication. The side effects can have a big impact on our emotional well-being, gaining weight, feeling ill-tremors, psychosis etc."

"I don't know anyone that's dealing with multiple personalities [...] I'm dealing with it all on my own."

All opportunities:

Provide children and young people with relevant, timely information, in a format accessible to the young person. Use Easy Read or social stories if appropriate.

Make sure the children and young people are clear on why a decision needs to be made, and are aware of the full range of feasible options. Support children and young people to explore the strengths and weaknesses of these options.



This resource has been developed by the Council for Disabled Children on behalf of the [Transforming Care Programme](#), part of NHS England. The barriers and solutions discussed in this resource are based on feedback from children and young people with learning disabilities and/or autism, explored in focus groups delivered by the Council for Disabled Children, [Inclusion North](#) and [Autism In Mind](#).

About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. The CDC membership is made up of a variety of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations.

CDC hosts the following networks and projects:

- IASS Network
- Independent Support
- Making Ourselves Heard
- Special Educational Consortium
- Transition Information Network

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