Embedding children and young people’s participation in health and social care services

Report on workshop held at Kings College London on 10th July 2013

This report summaries the ideas emerging from group discussions at a workshop organised by Louca-Mai Brady, a researcher at the University of the West of England, on the topic of ‘embedding children and young people’s participation in health and social care services’. The workshop was organised in collaboration with Investing in Children, Making Research Count, the Children and Young People’s Participation Learning Network and the University of the West of England, with the venue kindly provided by King’s College London.

The workshop was attended by over 100 professionals and young people, and reflected on the challenges and opportunities for children and young people’s participation in the context of wider changes in health and social care in England, as well providing practical examples from children and young people and organisations working with them. The day explored what it means to ‘embed’ children and young people’s participation within and across health and social care services, and what is required for children and young people’s participation to be meaningful, effective and sustained at individual, service and strategic levels. Presenters included Dr Maggie Atkinson, Children’s Commissioner for England and Amanda Allard, Principal Officer, Council for Disabled Children with presentations from Investing in Children, the Association for Young People’s Health, Young Minds, North Bristol Community Children’s Health Partnership and East & North Hertfordshire NHS Trust. Further details of the workshop, including presentations and a report from a young person who attended can be found at: http://younghealthparticipation.com/.

Children and young people’s participation – who participates and how?

Equality of opportunity and reflecting diversity

It was felt important to understand the diversity of children and young people (CYP) and provide opportunities for all young people who use health and social care (h&sc) services to participate, so that not just the most confident and articulate are involved. In order to do this participants discussed the need to address the needs of specific groups who may be less frequently heard (e.g. young children, disabled children and young people, those young carers and other groups who are perceived to be ‘harder to reach’ including CYP living in rural areas). It was also seen as important to involve parents and carers as well as children and young people themselves (especially for young children, disabled children and young people and those with serious or long-term health conditions). The specific needs of young adults and the transition of services from YP to adult were also seem as a key point for participation.
Creating opportunities for participation

It was acknowledged that CYP are more likely to be given opportunities to participate in some h&sc environments than others. It was suggested that this could in part be addressed by providing a variety of opportunities for CYP to be involved ‘in every way and at every level’ – from their own individual care to service delivery and strategic planning, while recognising that not all CYP will want or be able to be involved. Several participants suggested starting with the grassroots and having discussions with CYP about their individual treatment or the service they’re using, and then extending that to providing opportunities for participation in service planning and delivery as well as participation at a strategic level, including in research and evaluation. There were also discussions about how to provide awareness of participation and opportunities to be involved for CYP not accessing h&sc services on a regular or ongoing basis, for example through schools, youth clubs and other organisations working with CYP.

Making participation appealing and relevant to CYP

Participants felt it was important that opportunities for participation were presented to CYP in a way that made it feel interesting and worthwhile, and considering from the outset the training and support needs of young people participating and the staff working with them. The setting for participation activity was also felt important, with young people meeting somewhere welcoming and accessible and not necessarily in a formal or clinical setting.

As outlined above, participants said that participation in h&sc needs to reflect the diversity of CYP, and therefore provide different and creative ways in which CYP can be involved, and offer different options, rather than ‘one-size’ fits all or sticking with tried and tested participation techniques: ‘ask CYP how and when they want to be involved!’ People said that participation needs to be relevant to CYP’s lives and experiences as well as those of the service or organisation, and provide space for them to bring their own issues to the table. Issues of power and impact are discussed further below, but at this point it is worth mentioning the idea discussed of CYP needing to be given status as (for example) ‘experts by experience’.

Staff and organisations role in participation

Roles and responsibilities for participation

Participants said that supporting participation should not just be the responsibility of dedicated staff or projects, although there is a need for skilled participation workers to promote participation and support other staff. But it was felt that participation needs to be integral to everyone’s work and written into job descriptions: ‘all practitioners working with CYP need to understand why participation is important’.

In addition to participation expertise in the form of frontline staff there was also seen to be a need for participation champions at every level and in every h&sc profession including CYP, frontline staff, middle and senior managers, board level, commissioners, governing bodies and government.
Support for staff

In addition to the training and support mentioned above in relation to support participation, people felt that participation should be something that h&sc professionals are aware of from the start of their careers, and that it should therefore part of professional training and degree programmes (ideally delivered by or with CYP). Learning should also come not just from within the sector but draw on participation expertise and resources from other organisations and sectors, in particular the voluntary sector.

In an echo of the power issues discussed below several groups said that, in order to support CYP’s participation, frontline staff also need to feel listened to, and that they have a say in service and organisational decisions. Managerial and organisational support was also seen important in allowing professionals to feel able to take risks and be creative. Elected officials and senior managers in h&sc organisations therefore also need training and support to understand the importance of CYP’s participation and their role in supporting it.

Participants explored whether there needs to be a balance between incentives and sanctions to get all organisations to commit to embedding participation. It was suggested that commissioners and national bodies could play a key role, and that commissioners should monitor participation as well as service provision, and when commissioning ask bidders to demonstrate how they intend to involve CYP in the planning and delivery of services as well as providing resources to enable this participation to happen. Participants felt that Healthwatch should also play a role in changing cultures and promoting CYP’s participation.

Challenges and barriers

The complex and changing landscape

The complexity and variation within ‘h&sc services’ was seen as an issue and the fact that many CYP and their families will not see ‘health and social care’ as a system of which they are a part, but will instead identify with the particular services that they use. In terms of communication the language used by h&sc organisations and professionals was also seen as a potential barrier including the pervasiveness of jargon.

It was felt to be hard for services and organisations to think long-term (a key aspect of embedding participation as discussed below) in a time of change and uncertainty. Although current changes offer opportunities, concerns were also expressed that there was a risk that CYP’s voices could be lost and that CYP’s health/participation can sometimes be seen as less important than that of other groups, especially when seen as competing for limited resources.

Prioritising CYP’s participation within existing structures and processes

CYP’s participation in h&sc was felt to still often be seen as an add-on and something that would be nice to do, rather than an integral part of a quality service and therefore worthy of investment of time and resources. Some participants said that managers can appear to be more concerned with target
outcomes than outcomes of participation. It was felt that some h&sc organisations, services and professionals are a lot more engaged with CYP’s participation than others. GPs in particular were highlighted as often lacking awareness in this area, and at the level of participation in individual service provision a need was expressed for doctors in general to be open with CYP about their health and diagnosis (eg HIV), talk to CYP about treatment impacts and do more ‘to be understood and to understand CYP’, especially those who are growing up with illness or impairment.

Even when there is an understanding of what ‘good’ participation is and a commitment to embedding it, this was said to often be hampered by pressures related to other targets and priorities. While the need the need to evidence impact was acknowledged, participants said that there was difference between outcomes/monitoring information required by h&sc bodies (generally quantitative ‘hard’ data) and that most useful to CYP and their families (often qualitative). There was also fear of over-promising to CYP about the difference their participation can make, when h&sc systems and processes create barriers to change or mean that change can take a long time.

Understanding participation and children’s rights

Participants talked about not knowing where to start with participation, even when there is a willingness and interest, along with a common perception that ‘good’ participation is difficult, time-consuming and expensive. Participation in h&sc was felt to be often seen as synonymous with ‘listening’ and ‘consultation’ – but that there is a need to separate out how and when these words are used and the meaning behind them, as well as how CYP’s participation fits with the agendas of public engagement and involvement in h&sc. The focus on participation on children’s rights and the UN Convention on the Rights of the Child was seen as key. Meaningful and embedded participation is about more than consultation, review and ‘having a voice’ (although people agreed that these have a place) and should include the planning and initiation of ideas. But although a need for standard definitions, minimum standards and guidance on good practice was identified by many participants, there was also felt to be a potential danger of institutionalising participation if it became too formalised and structure.

Power

Power was raised as an issue, both understanding who exercises it and the importance of sharing power through meaningful personal relationships. There was also felt to be a danger that some CYP may find it hard to ‘tell it like it is’ because they do not feel empowered to do so, particularly in a clinical setting, or are worried about the consequences. But this was not just about power of adults vs. CYP but also power relationships between adults, including the suggestion that the structures and hierarchy within the NHS and other public bodies in particular don’t support participation or power-sharing. If challenging people to break down hierarchies and share power (as discussed below), participants also felt that there was a need to be careful not to create a situation where people feel overly criticised for their practice rather than supported and encouraged.

Related to these issues of power and the points made about organisational cultures above, it was also suggested that fear of criticism and entrenched ways of thinking and doing things can also cause resistance to change and therefore to meaningful and embedded participation.
Challenges to recruiting young people and planning involvement

Deciding when and how to involve CYP, and the ways in which to do this (eg reference/advisory groups or outreach work) was seen as challenging by some participants, given the equality and diversity issues outlined above. It was also thought to be important to work with gatekeepers including as parents, carers and services who, by wanting to protect CYP (especially young children or those perceived to be vulnerable), may also prevent them getting access to information about participation opportunities.

Participants also thought there might be particular challenges to recruiting CYP in h&sc settings due to the fragmented and varied nature of services and the contact CYP have with them, the fact that they may be particularly vulnerable when using these services. There are also perceptions of a tension between participation rights and safeguarding responsibilities, especially when CYP are perceived to be vulnerable.

Although, as outlined above, it was felt to be important to get the views of parents, concerns were also expressed that they can be seen as a proxy for the views of the child and there could be potential conflicts of interest between parents and carers. Other concerns raised around were around whether long-term involvement in formal participation activity could potentially ‘institutionalise’ some CYP, particularly where participation activity focuses on particular experiences (eg using mental health services, looked after CYP, disabled CYP, those affected by sexual exploitation). Participants discussed how there may be times when offering participation opportunities would not be appropriate (eg acute health or other crisis) and professionals would need to consider whether opportunities could be offered at a different time or in different circumstances.

Embedding participation

Further to the issues outlined above, a number of key ideas emerged from the discussions on what workshop participants thought needed to be in place for CYP’s participation to be embedded in health and social care services and settings:

Integrated and integral

The current changes in h&sc, and increasing interest in CYP’s participation and public involvement and engagement, were felt to provide opportunities as well as challenges. For CYP’s participation to be embedded workshop participants felt that it needs to be a routine and central part of what all h&sc services, organisations and staff do, integral to organisational purpose, structure and processes and fundamental to effective service delivery and CYP’s wellbeing. There needs to be sustainability and a commitment to consistency, rather than participation being linked to one-off projects (although such projects can be catalysts to start embedding participation). It needs to be planned from the outset and not an after-thought or add-on, with sustainable and realistic funding and resources, long-term planning and a commitment to consistency. It needs to happen at all levels including individual care, planning and delivery of services, evaluation and feedback, role development and recruitment, staff training, strategy and commissioning - incorporating participation, creativity and a listening culture into everyday work.
Meaningful

Embedded participation needs to be linked to what’s important to CYP, ‘not just ticking a box’ and also be planned in a way that makes it interesting, accessible and relevant to CYP’s lives. In order to make the case for participation from a clinical perspective, participants thought it should also be seen as integral to the quality of service delivery, e.g. are CYP more likely to engage with services and treatment if they feel that they’re being listened to, in a service which is seeking to meet their needs through speaking to them or their peers rather than making assumptions?

Embedding participation was felt to be about getting services right through CYP being empowered to demand better care, not being dependent on professionals changing voluntarily. So a culture change in which CYP work alongside h&sc services and organisations to create more accessible and user-friendly services which better meet their needs, underpinned by a commitment by senior managers and commissioners to promoting and monitoring participation.

Well-supported

As well as drawing on existing resources (see ‘collaboration’ above) support, guidance and training on participation were seen as important for CYP, staff and organisations. When planning participation services and organisations also need to consider reward and recognition for CYP, including considering issues of payment, accredited training etc.

Inclusive and flexible

Reflecting the diversity of CYP and equality of opportunities issues identified at the start of this report, it was felt that information about participation opportunities, what will be involved and benefits needs to be easily accessible to every CYP using h&sc services, their families and those working with them – linked to school and other social and education programmes.

People felt that it was important for CYP’s participation in h&sc to be flexible, with a combination of formal and informal (eg everyday conversations and feedback) participation to improve dialogue and engagement.

Realistic

Embedded participation should start from the grassroots – ‘start small, participation does not have to be big’. It was also felt to be important not to over-promise, even with the best of intentions, and that it was better to be honest with CYP about what can and cannot change and why, but also challenge existing structures and processes where possible and appropriate.

Participants thought that h&sc organisations needed to be better at costing up and committing the time and budget necessary for the participation they are planning, and if budget is limited explore creative alternatives or look to the voluntary sector for examples of how to support participation with limited resources.
Collaboration and sharing learning

It was seen as important that good participation be based around collaborative working – within and across organisations and between adults and young people. Shared ownership was felt to be essential, with CYP and adults supported to work together and services and organisations being open to criticism and change. Outputs and outcomes from participation and resources and other outputs should be shared within organisations and more widely (eg online), including information by and for young people. Participants also thought that existing guidance such as ‘Hear by Right’ and ‘You’re Welcome’ and other available resources should be more widely disseminated within h&sc.

Demonstrating impact

It was thought to be really important to be clear about who benefits from participation, how and when – and to demonstrate that it is meaningful for all involved. In order to understand how participation is working and how it can be improved CYP’s participation should be constantly reviewed and evaluated, with input from CYP, staff and organisations. ‘It needs to be recorded, reported and fed back to service users’. It was seen as really important to be able to demonstrate the impact and outcomes of participation, with CYP and adults involved seeing that something has happened as a result of their participation and feeling that their contributions are valued. Participants said that being listened to needs to be linked to changes in service delivery, demonstrated though organisational monitoring against measures set by CYP. ‘Don’t ask the questions if you’re not going to act on the answers’ and also involve CYP in deciding what those questions should be. But h&sc organisations should also remain aware that participation is not just about outcomes and change, but also about the quality of the process and an ethic of practice and co-learning.

Next steps

This workshop was part of an ongoing project on the same topic and further information will be posted on the project blog (http://younghelparticipation.com/) as the work progresses. Contributions to the debate, including responses to this report, are also welcome via the blog.