YoungMinds Good Practice

PUTTING PARTICIPATION INTO PRACTICE

A guide for practitioners working in services to promote the mental health and well-being of children and young people

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YoungMinds 2005

CONTENTS

FOREWORD

I am very pleased to endorse this publication – which is a real first for child mental health services.

This publication sets out to put participation into practice and provides a clear framework for embedding children's voices and views in decision making about their individual treatment and care and in the development of services. We have so much to learn from children and young people about what they need, and what they find helpful from services and what they do not.

Examples of peer mediation, peer advocacy and involving young people as researchers are all innovative ways of making sure that participation really does put children and young people at the centre of their care.

I know that this agenda is immense and complex but together I am sure we can make real changes in improving children's and young people's lives and health.

Professor Al Aynsley-Green
Children's Commissioner for England

This guide

This guide by YoungMinds, the national children's mental health charity, has been written for staff working in specialist Child and Adolescent Mental Health Services (CAMHS). It provides practical information about the participation of children and young people that staff can develop to suit the requirements of their particular service.

However, children's mental health and emotional well-being is the **business of everybody** and 'comprehensive' CAMHS are all services working to restore and promote the emotional well-being and mental health of children and young people. Research has also highlighted the importance of multi-agency approaches and collaborative working, and thus, this report is also for those working in other health settings, education, social services and the voluntary sector.

The material draws upon the experience of a number of YoungMinds' researchers and consultants in undertaking research and mental health service consultations involving young people. It considers evidence from work that young researchers have undertaken and is backed by an overview of the learning from a wide range of fields, including social care, youth counselling, services for children with disabilities and health promotion.

The national context

Children's and young people's participation is at the centre of the government's Every Child Matters: Change for Children programme and the delivery of the *Children's National Service Framework – the Mental Health and Psychological Well-being of Children and Young People* (2004). In *Learning to Listen* (2001), the government set out its commitment to children's and young people's participation in "the design, provision, and evaluation of policies and services that affect them" and laid down a requirement that all government departments produce action plans for the promotion of children's and young people's involvement in their departments.[1]

Since 1991, there has been a strong public policy push towards an active approach to involving children and young people, not just in developing services but in active involvement in their individual healthcare and education. A lot of work has been achieved by the NHS Expert Patient Programme and PALS (Patient Advice and Liaison Services). And across social care, there have been considerable achievements, for example, childcare reviews, the promotion of advocacy and children's rights services, complaints procedures and service consultations.

The importance now attached to involving health service users is summed up by the following quote from the Executive Summary of the Department of Health report published in 2004, *Patient and public involvement in health: the evidence for policy implementation:*

"The involvement of patients, carers and the public in health decision-making is at the heart of the modernisation of the NHS."[2]

Key policy drivers for involving young service users

"The active participation of children and young people has indeed become a key theme across a broad range of service delivery. It is no longer just advocates of children's rights who claim 'participation' to be their core philosophy. All organisations concerned with children and young people now promote participation as a 'central issue'. People have begun to acknowledge that children and young people have a right to be heard and, when listened to, can play a vital role in the planning and delivery of services."[3]

Developing the participation of children and young people in the services that they receive from health, social care and education providers is no longer an optional 'add on' for professionals – it is central to the current policy documents, government legislation and guidance underpinning the delivery of public services. In short, it is something that all professionals working with children and young people must address.

Important to consider are the following:

- The **Health and Social Care Act 2001**,[4] the **Education Act 2002**,[5] also significant government initiatives such as the **Children's Fund Partnerships** (where consultation with children and young people is central to the work supported by the local Children's Fund programmes), the **Connexions Services, Quality Protects** and **Choice Protects**. The involvement of children, young people and parents was a consistent theme running throughout the **Kennedy Report** inquiry into the Bristol Royal Infirmary.[6]

- *Working Together: giving children and young people a say*,[7] the statutory guidance for schools and LEAs on pupil participation produced by the Department for Education and Skills (DfES) in 2004.

- **The Children Act 2004**[8] and the development of **Children's Trusts**[9], where new requirements for local authorities and other agencies working with children and young people to work collaboratively are set out, with one of the five 'essential building blocks' being a child-centred, outcome-led vision – which must be informed by the views of local children, young people and their families. A number of these emerging trusts are now setting themselves specific targets through local Public Service Agreements.

- **The National Youth Agency's 'Hear by Right' Standards** for the involvement of young people in decision making – which many local authorities have adopted and are working towards.[10]

- Of specific relevance to practitioners in CAMHS, the framework for developing 'comprehensive' CAMHS (*Improvement, expansion and reform: the next 3 years, priorities and planning framework 2003-2006*)[11] has, as one of its 'underlying principles', that the commissioning and delivery of services should be informed by, amongst other things, stakeholder views – of which children and young people using services constitute an important group.

The appointment of the first **Children's Commissioner for England** on 1st March 2005 gives momentum to this requirement to involve young people, with the Commissioner having a remit to:

- Act as an independent voice for children and young people; to seek their views, to identify their needs and to bring their concerns to the national arena.

- To look into any matter concerning the well-being of children and young people.

- To initiate inquiries on behalf of children and young people.

The changes to complaints procedures (which included the Children's Rights Director for England consulting young people about these proposals)[12] and the plans to involve children in the inspection of local services noted in the draft green paper for youth, are other areas of policy likely to exert a significant influence on all services for children and young people in the future.

Finally, and illustrating that all of these developments have international relevance, the **UN Convention on the Rights of the Child and Article 12**,[13] as ratified by the government in 1989, emphasises the rights of children to express their views, and have their views taken into account, in any matter affecting them. The Convention declares the human rights of children as individuals in their own right, but it also recognises that children are vulnerable by placing their rights to participate alongside their right to protection and the provision of services.

What does this mean for staff in children's mental health services?

For many staff working in services for the mental health and well-being of children and young people, including those in specialist CAMHS, how to devise and implement systems for positively involving young people or to develop working in a participatory way, can seem a complex task. There are a number of reasons why, including:

- Much of the literature on participation or user involvement discusses areas other than CAMHS, notably social care provision for children and adult generic health services – and as such, has not provided a sufficient focus on the issues of concern to those in children's mental health services.

- The issues are complex and there is confusion over the language and different terms used.

- In the child and adolescent mental health field, there is a history of this issue being largely overlooked.

- The stigma that still accompanies discussions of 'mental health', 'mental illness' or poor emotional health which can make it hard to engage children, young people and their families directly – and can result in many wanting to detach themselves from services as quickly as they can, once their needs have been addressed.

- Worries about 'overloading' children and young people who may be seriously ill, highly vulnerable and already facing many changes and choices.

This guide by YoungMinds is intended to address some of these concerns. Throughout the document, case studies are used to illustrate some of the ways in which the participation of young people has been developed. Both the advantages and disadvantages of different approaches are outlined, and in Section 3, a range of resources for practitioners is summarised.
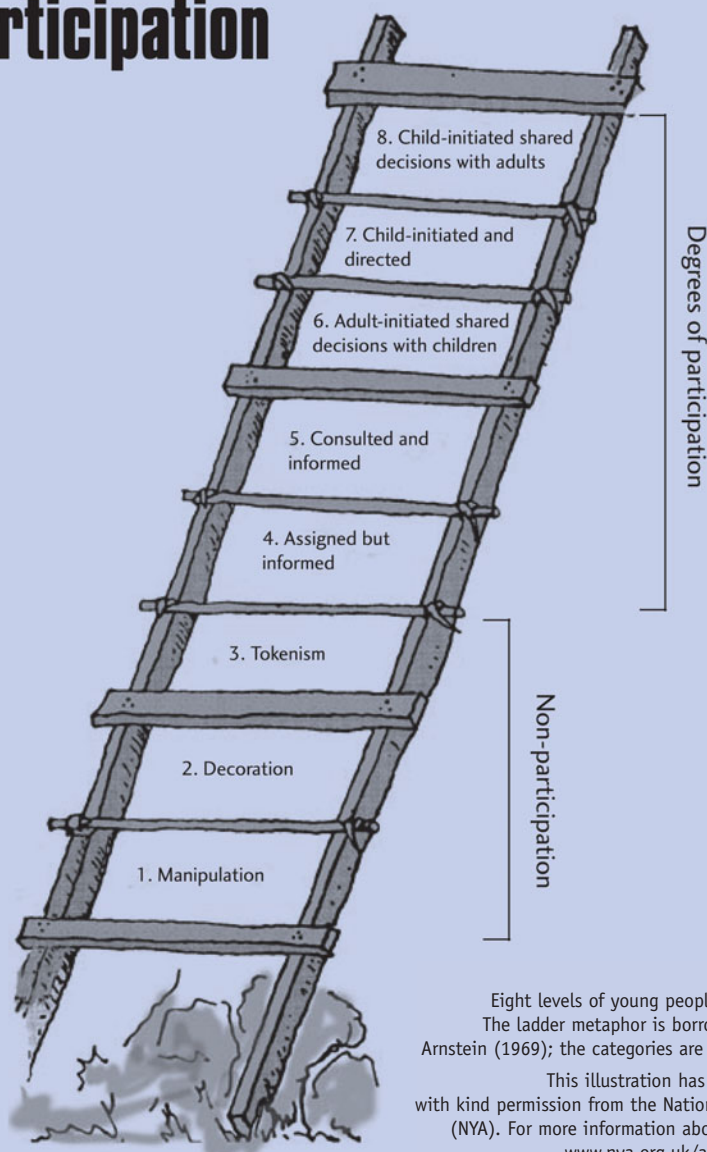
Terminology

'Participation', 'user involvement', 'consultation' and promoting 'inclusion' – all are terms that are often used when talking about how to improve existing public services in the UK. However, there are many different definitions given for these concepts, and meanings can differ depending on the context in which they are being used. Part of the problem for practitioners looking to develop user involvement is that often the words are used interchangeably and can refer to a vast array of activities:

" 'Consultation' can mean many things – from adult-led activities aimed at exploring opinions that might be acted upon later, to an approach that encourages and supports child-initiated and child-driven approaches and self-determination. Participation in decision-making means 'taking part' but can cover a huge range of ways to be involved in influencing decision-making and influencing change."[14]

The following draws on the *Listening to Children and Young People Project*[3] and *Practice Standards in Children's Participation* by Save the Children[15]:

- **INVOLVEMENT** is a generic or umbrella term covering a range of activities. These can include information giving and receiving and consulting on specific issues. It does not define the extent of power young people may have to influence the process or outcomes.

- **CONSULTATION** can mean many things from adult-led activities aimed at exploring opinions that may be acted upon later, to approaches that encourage and support child-initiated and child-driven approaches and self-determination. Consultation can be undertaken on a large formal scale or on a personal, informal level. It is often equated with participation – but crucially, it is usually adults who hold the power to decide what to do with the information.

The Ladder of Participation

8. Child-initiated shared decisions with adults

7. Child-initiated and directed

6. Adult-initiated shared decisions with children

5. Consulted and informed

4. Assigned but informed

Degrees of participation

3. Tokenism

2. Decoration

1. Manipulation

Non-participation

Eight levels of young people's participation. The ladder metaphor is borrowed from Sherry Arnstein (1969); the categories are from Roger Hart.

This illustration has been reproduced with kind permission from the National Youth Agency (NYA). For more information about the NYA visit: www.nya.org.uk/activeinvolvement

- **PARTICIPATION** refers to young people taking an active part in a project or process, not just as consumers but as key contributors to the direction and implementation of it. Young people are proactive in this process and have the power to help shape the process – their views have the same weight as the adults they are working alongside.

The issue of how much power young people have in these different processes is important, with some writers mentioning models such as 'ladders' or 'pathways' of participation. These models aim to help practitioners think about their decision-making processes and the power balance between professionals and service users, with the idea being that they can then identify the actions needed to progress towards effective or more meaningful user involvement:

"These models help highlight the need to understand and distinguish different levels of empowerment afforded to children and young people in organisations. They prompt us to ask: what level of participation is appropriate for which activities; what level

does a project or activity aspire to; at what level does it actually operate?" [16]

However while these models may be useful in helping organisations to clarify the stage they are at in supporting young people's involvement, caution is needed since it may not always be feasible or appropriate for an organisation to aspire to the top levels of the ladder, nor do all children or young people want to be involved:

"Levels and means of involvement need to be negotiated with children and young people. This makes it more likely that they will be comfortable with the process and have a sense of ownership of it. It also avoids raising false expectations." [17]

The benefits of participation

"When it is carried out thoroughly and sensitively, consultation with children and young people can yield vital information and insights to assist professionals in the planning and provision of better, more accessible and more appropriate services." [17]

"Adults can reap tangible benefits from working in association with children. Developments in professional practice over the last couple of decades suggest that adults, by modifying their methods as necessary, can learn a lot from such processes. The increasing use of games in group work, training events and team building is an obvious example." [17]

"Patient involvement increases patient satisfaction. Benefits also include greater confidence, reduction in anxiety, greater understanding of personal needs, improved trust, better relationships with professionals and positive health effects." [2]

In many ways, this is the heart of the matter for staff working in mental health settings when considering why to involve young service users – **what benefits, positive outcomes or changes will this bring** – and from a variety of different fields, there is strong evidence that the effects are positive, as the quotes above illustrate.

In Carolyn Mumby's work for Youth Access on building user involvement in youth counselling services,[18] the benefits of user involvement are set out for different groups:

For **organisations**, the following are identified:

- **Improved access to services** – consultation and involvement of young people enables the organisation to assess its suitability for different user groups, to find out how the service operates and to target specific client groups to whom they wish to ensure better access.

- **Development of more responsive services** is encouraged through the gathering of feedback from service users. Providers can assess whom the service is reaching, how it is being used, whether services are meeting needs and where there are gaps.

- **Improving service performance** is aided through the measurement of client satisfaction, which provides service providers with valuable evidence upon which to base changes in practice and to demonstrate responsiveness to client needs.

- **Informed planning and development** – the involvement of young people can help to highlight the necessity for introducing new services and can bring new energy and ideas to an organisation.

- **Increased accountability** to the management body, funders, staff, other agencies a service works with and young people themselves.

- **Supporting staff** – by involving young people, the support and professional needs of staff can be identified more accurately; there will be greater job satisfaction for workers who are motivated to improve services for young people and user involvement allows staff to develop more insight into young people and their needs.

For **young people**, involvement is noted to provide:

- Opportunities for them to share both their frustration and appreciation of the service.

- Recognition that their views, opinions and ideas are valued and these can make a difference.

- An increase in confidence, self-esteem, experience and skills and becoming more independent and prepared for further participation in civil society – that is, becoming empowered. Services may also become more 'young-person friendly'.

Benefits for **funders** include:

- Knowledge of user satisfaction and how responsive the service is.

- Knowledge of service strengths or weaknesses and how a service is attempting to address these.

Benefits for the **wider community** are also noted on the basis that young people who become empowered are more likely to make a positive contribution to society.

The benefits of involving parents

Alongside the discussion of the benefits to young service users, an important consideration for staff working in mental health settings is the involvement or participation of parents or carers. This can be especially difficult when, for example, the views of young people and their parents differ, or where there are issues of patient confidentiality to consider.

However, the findings about parent involvement are positive and highlight the need for service providers to consider this group when thinking about participatory work:

"Being involved empowers parents and helps them to feel they have some control over their own and their child's lives, which can lead to lower levels of stress for families and better use of services. Participation not only helps develop better services, it also improves relationships between professionals and parents and helps parents to be active participants in planning for their children's lives."[19]

The impact on clinical outcomes

There is evidence, at least strongly suggestive, that participation improves clinical outcomes. The evidence from the evaluation of the CAMHS Innovation Projects[20] (with case study 1 being based on one of these projects) shows the crucial importance of staff skills and methods in gaining the participation of young people, both in engaging them in therapy and in their willingness to go on working in the therapeutic situation. The evaluation highlighted the need for time and a sensitive and skilled approach in enabling young people to talk about what they really think and feel and that:

"Young people highly valued opportunities to express themselves and to be truly listened to. This could make a helpful dialogue possible, so that young people could then benefit from a whole range of services."[20]

The evaluation findings highlight the following as the key elements in a service that 'works' – services need to be acceptable, to be provided in a non-stigmatising environment, to be welcoming, respectful and empowering; they need to seek to engage children, young people and their parents/carers, with professionals in services being committed to consulting with and acting on children's and families' views.

Case Study 1: Behaviour Resource Service (BRS), Southampton

Developed as a CAMHS Innovation Project, the BRS has been operational since January 2000. The service, which is at Tier 4 (the most specialist level of service), offers a short-term residential unit for young people with complex needs who are considered to be at serious risk and who require an intensive multi-agency assessment. There is a strong emphasis on inter-agency links with services within the community and on providing training and support for families to help them address a child or young person's needs.

From initial stages of contact, staff at the BRS work to actively involve young people, parents and carers. Their views on care plans are incorporated from the outset and the unit has developed specific pro-formas for recording the views of young people. On a regular basis, service user views are sought via a number of different means and fed into the care planning process. This includes individual meetings with staff, a suggestions box and via each young person's 'reflections book' which is where staff and young people plan their day and then complete reflections of that day.

Current work at the BRS to develop user participation and ways of consulting with young people includes: working with young people to develop more user-friendly care plans; looking at other ways for gathering feedback such as email and facilitation of a user group and work on developing an evaluation tool for parents, carers and referrers to the service.

A member of the BRS staff is part of UCIS, the User Carer Involvement Subgroup, which meets on a monthly basis in Southampton. Drawing together staff from many different agencies working with young people and families in Southampton, the group shares views and information about planned activities to develop user involvement in the local area.

Further information: Aishea Ziya, Senior Practitioner. Tel: 02380 799 100. Email: aishea.ziya@southampton.gov.uk

Young people's views about CAMHS

The valuable information gained through involving young people, or consulting with them about the CAMH services they receive and find acceptable is evident through a growing body of literature, including two national studies of CAMHS undertaken by YoungMinds over the last five years[21][22] and the evaluation of the CAMHS Innovation Projects mentioned in the previous section.[20] Areas of particular relevance include:

- Young people's perceptions and awareness of mental health and their need for information about mental health service provision and mental health problems – these play a key role in whether young people seek or accept help and the timing of this.

- The importance of the language and terms used when consulting with young people and seeking their views about CAMHS.

- Young people's views about the sort of staff and staff skills they find helpful.

- Issues to do with stigma, confidentiality and consent to treatment and medication.

- Issues to do with treatment regimes, choice and feeling informed.

- The style of service delivery and how this impacts on the take-up of service provision.

It is also clear that many young people want to be consulted and involved – and are capable of making meaningful, informed choices if given the opportunity to do so (laying firmly to rest a fear that the clients of CAMHS may not be sufficiently well as to be able to make rational choices).[23][24]

Learning from YoungMinds' studies and consultancy

From YoungMinds' experience in the field, two particular questions need to be asked:

1) Who to consult – notably how to involve non-users of services or those who fail to attend. This is an important group in terms of perhaps understanding why they did not use a mental health service and thus identifying ways to improve engagement with services.

2) When to consult or involve young people – this question arises from the views expressed by many young people using CAMHS (in particular Tier 4 services) that often at the time of coming into contact with CAMHS, or being admitted, there is so much going on and so much information being given that it is hard for young people to take all of this in and to become involved in a meaningful way.

Building up trust in the professionals working with them is critical and takes time. At this point, young people may be seriously unwell – and there may be the added complication of a young person having a learning disability or some other form of difficulty. Equally, at the point of discharge or afterwards, some young people talked of having 'moved on' and resuming their lives and of not wanting to re-visit their experiences of CAMHS. This highlights the importance of flexibility, of providing a 'listening culture' and openness between clinician and patient, of thinking about different ways for involving young service users, and of respecting a young person's right not to get involved if they do not want to.
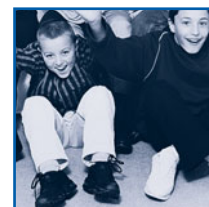

Case study 2: Barnardo's Participation Worker, Leeds CAMHS

With two year funding from the local Primary Care Trust (PCT) and line managed by Barnardo's, a Participation Worker is undertaking a range of training and information sharing in order to help develop participatory work with young service users across all levels of the local CAMHS.

The aim of the work is to encourage CAMHS to take account of the views of young people and carers through the use of different participation approaches. Feedback will be taken to teams, to management and to service commissioners within CAMHS, ultimately informing the shape and delivery of local services. These developments will be taken forward as a partnership between Barnardo's, service users and carers and staff in CAMHS, building a participatory approach that is realistic and sustainable within these services.

A young people's advisory group has been recruited to work with the Participation Worker; so far, they have been involved in designing promotional materials and questionnaires. These young people were identified via local voluntary and community groups. The Participation Worker has also been meeting regularly with staff from CAMHS, including offering training about service user participation. Each of the local CAMHS teams has volunteered a named linkworker to take forward this process.

Further information: Nicola Swales, CAMHS Development Worker.
Tel: 0113 240 8368. Email: Nicola.swales@barnardos.org.uk
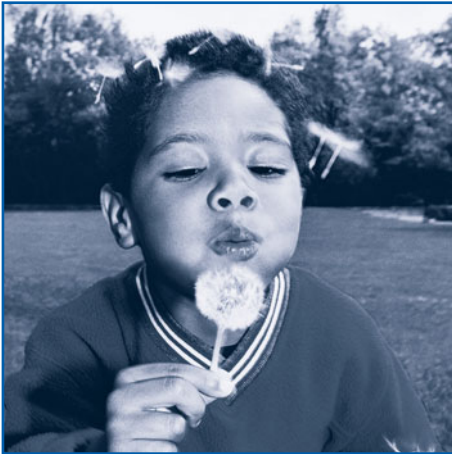
Involving young people in research and evaluation: ethical considerations

Alongside the growing recognition of the value of user views about mental health services, which to some extent has run alongside the impetus towards participation and involvement, there has been a general move away from large scale survey approaches towards methods that more actively involve service users in research about mental health services.

Starting first with adults, the last decade has shown increasing activity involving young people in this way.[26] Furthermore, there is now more research actually involving young people as researchers and this is something many practitioners in CAMHS may be involved with in the future, or may be interested in developing.

Whilst referring to adults, work by INVOLVE (formerly Consumers in NHS Research)[27] outlines some important reasons for involving service users in health service research and development:

- People who use services can offer different perspectives.

- People who use services can help to ensure that the issues that are identified and prioritised are important/relevant to them and therefore, to health care as a whole.

- This can ensure that money and resources are not wasted on research that has little or no relevance.

- User involvement can help to ensure that research does not just measure outcomes that are identified as important by professionals.

- It may help with the recruitment of their peers for the research.

- This may help in contacting other groups that are difficult to access such a people from Black and minority ethnic communities.

- The people who use services can help to disseminate the results and work to ensure that changes are implemented.

- The process, if done well, can help empower people who use services.

Case study 3: Hampshire Healthy Schools Programme

Through the Healthy Schools Programme, three schools in Hampshire developed peer support: in an infant school, Year 2 pupils are trained to run the 'friendship stop' where pupils who are feeling lonely can find support; a playground buddy system operates in a junior school, supplemented by the pupils running the games store each break time, and in the senior school Year 10 pupils have received training to offer peer support for other pupils on issues such as bullying and bereavement.

Further information: Glynis Wright. Tel: 02380 816 139.
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The DfES briefing on promoting participation through the National Healthy School Standard highlights the wide ranging benefits arising from pupil participation:

"Healthy schools are finding that participation has a positive effect on their ethos, school improvement programme, teaching and learning, inclusion, health and wellbeing and the reduction of inequalities. Through activities such as peer support it also reduces bullying, improves school safety and supports children and young people's emotional and social development. More importantly, children and young people want to be involved in the life and running of their school. It is their entitlement to be involved and it leads to democratisation in which leadership and responsibility are shared and where both adults and children feel empowered."[25]
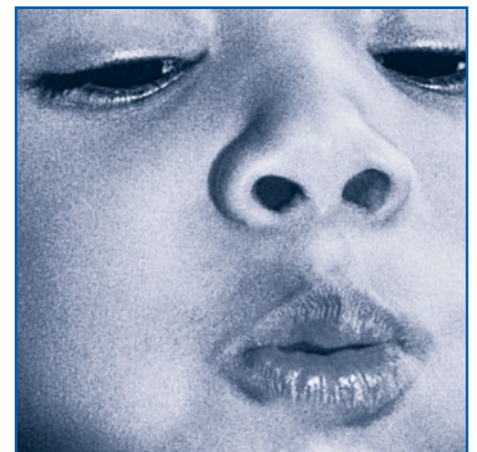
Talking specifically about **involving children and young people in research**, either as participants or actual researchers, the following reasons have been put forward:

- It may produce better research – involving young researchers may help in collecting quality data and can also be a more ethical and democratic way of undertaking research.

- It is one way of encouraging young people's participation, of involving them as citizens and can increase their knowledge and access to decision-making structures.

- It can aid personal development with young researchers gaining knowledge, skills and confidence.[28]
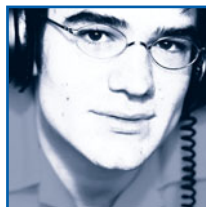
However there are important questions and ethical issues that need to be considered when involving young people in this way. In Kirby's work for the Joseph Rowntree Foundation,[28] the question of which young people should be involved as young researchers is explored, including how they might be recruited, trained and supported. The possible barriers they might face, the time required for planning, the handling of sensitive information, safety measures and parental consent, are other matters raised.

Claveirole[29] makes similar points emphasising that it is important to find a balance between protecting young people's best interests and recognising their right to exert their competence. This review and the booklet *Health Care Choices: Making Decisions with Children* by Alderson and Montgomery,[24] provide invaluable overviews of the following ethical considerations:

- Children's entitlement to confidentiality and the boundaries of this.

- Informed consent – including the *Gillick* decision and the requirements to gather parental consent.

- Consideration of a child or young person's mental state.

- The provision of support should a young person become distressed as a result of a research interview.

- Appropriate methodologies and recognition of the power imbalance between adults and children that may require careful monitoring in research situations.

A particular problem that also needs to be considered in planning research with young people about CAMHS is that often services work with young people who have been referred by others and where the young person may not think that they have a problem or may not want to change; it may also be the case that the possessor of the primary problem is not the young person.[30]

Case study 4: Liverpool Participation Standards for Children

In Liverpool, a number of agencies undertook a consultation exercise in 2003 to draw up a set of Participation Standards for young people. Young people's views of the draft standards were gathered through a number of key events around Liverpool including one at Liverpool Football Stadium and a launch event at Merseyside Maritime Museum.

The standards have been produced to support all agencies in the process of engaging with and consulting with children and young people. It is hoped they will help to ensure that work is well planned, has enough resources and is effectively delivered.

In addition to the development of the standards, a number of other consultation exercises with children and young people have taken place in Liverpool over the last five years. The Royal Liverpool Children's NHS Trust supported work looking at the issues that were important to its users, with *The Children's Society in Liverpool* and staff from Alder Hey Hospital working together to seek the views of children and young people. Other groups of young people involved in consultations include: disabled children and young people, where the *Diversity and Difference Group* was set up to promote collaboration between service providers and users, and young people looked after by Liverpool Social Services Directorate.

Further information: John Hogan. Liverpool Children's Fund. Tel: 0191 260 9318. Email: john.hogan@liverpool.gov.uk

Learning from YoungMinds' research

Similar issues were repeatedly raised through the YoungMinds study *Where Next?* which explored ways of delivering in-patient CAMHS, in particular flexibility of approach.[21] Some of the key points from this work were:

■ That **initial information** about the consultation/data to be gathered is important and that ideally this should be shared in person by someone known to the young person, backed by written information.

■ **Roles need to be clear** – who will interview them, when and where this will happen, what will happen afterwards to the information?

■ It is very helpful to involve young people themselves in the design of any paperwork, questionnaires and so forth, to ensure that the language is relevant and age-appropriate.

■ It is important to **stress confidentiality** and to explain the boundaries of this, both verbally and in written form.

■ **Qualitative research methods** perhaps work better than quantitative in engaging young people and allowing them to raise issues that concern them personally.

In YoungMinds' most recent research study, *Minority Voices*, similar issues emerged.[22 31] Of key importance, here, are the following:

■ The need to consider **translating into different languages** the research information materials and also, to consider whether **interpreting support** is needed in carrying out the research.

■ Exploring **different and non-traditional routes for sharing information** about the research in order to encourage participation by marginalised groups – in this study, the focus was on young people from Black and minority ethnic communities and study participants highlighted the crucial role played by the media, local community and faith groups.

Case study 5:
Community Adolescent Mental Health Services, Darlington

The Durham and Darlington Adolescent Mental Health Service is a partner in *Investing in Children (IiC)*. This is a multi-agency initiative concerned with the human rights of children and young people that has been developing effective models of practice over the last six years.

Through this initiative, the adolescent team wrote to thirty service users in 2002 inviting them to an 'Agenda Day'. This is an event run by young people without the influence of adults, where young people are encouraged to discuss issues that they think are important and to put together an 'agenda'.

From this event, ten young people agreed to take forward this agenda and to begin a dialogue with local mental health service providers. *IiC* supported the young people while they undertook research about the issues they wished to raise and developed their arguments – this support being seen as important in capacity-building and in providing young people with important skills and the confidence to engage with professionals in this way. From these activities, important points have emerged about the delivery of local services including their location and hours of operation.

Future plans include *IiC* writing up the practice model that has emerged from their work in the mental health field; this will include a research phase with local CAMHS colleagues and analysis of the process.

Further information: Liam Cairns, Project Manager. Tel: 0191 386 7487.
Email: Liam.Cairns@durham.gov.uk

Advocacy support

The provision of advocacy support is an important avenue through which young people can participate and have 'a voice' in expressing their views about mental health services:

"Advocacy is about speaking up for children and young people. Advocacy is about empowering children and young people to make sure that their rights are respected and their views and wishes are heard at all times. Advocacy is about representing the views, wishes and needs of children and young people to decision-makers, and helping them to navigate the system." [34]

In the Department of Health's guidance *National Standards for the Provision of Children's Advocacy Services,* [34] it is noted that advocacy services should provide independent and confidential information, advice, advocacy, representation and support. It is highlighted that it is important that children and young people have an advocate of their choice. This can include parents or other relatives (informal advocacy), friends or relatives of the same age (peer advocacy) as well as formal advocacy provided by specialist agencies.

Complaints procedures are also important in terms of making sure children's views are fed back into service improvements. Children's social services complaints procedures are being revised so that problems are dealt with quickly and effectively.
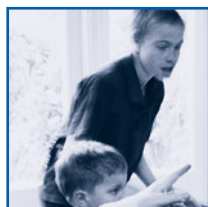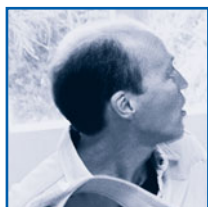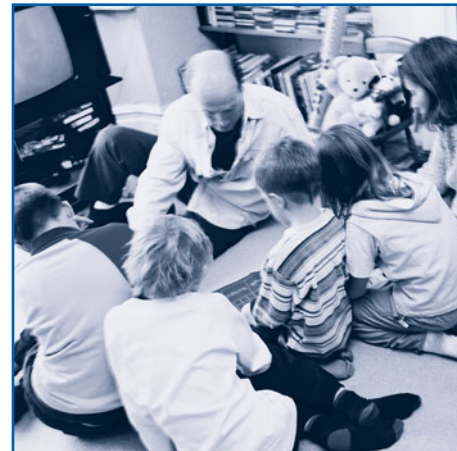
Case study 6: The Headspace Project, Somerset

Developed by Advocacy in Somerset and closely involving a group of young people, The Headspace Project has developed a self-advocacy toolkit for young people who are in in-patient CAMHS. [32] The aim is to equip young service users with the information and skills needed to express their wishes and feelings and to be able to challenge and make informed decisions about their care and treatment within CAMHS.

The project has been funded under the DfES *Ready Steady Change* [33] initiative (www.crae.org.uk) with the original idea for the toolkit coming from staff providing advocacy to the local Tier 4 unit and becoming aware of the deficits and gaps in information being offered to young people, in particular, with regard to complex issues such as consent to treatment.

The toolkit has been written and designed by young people with support from a member of staff from Advocacy in Somerset, and young people at a local arts college are now designing the toolkit graphics.

Further information: Joe Roberson, Project Leader. Tel: 01823 324 762. Email: headspace.toolkit@virgin.net

Case study 7: The Phoenix Centre, Cambridge

The Phoenix Centre is a specialist in-patient unit for young people aged 12-18 with eating disorders. With PCT funding, a Head of Patient and Parent Involvement has been in post since January 2004 working 15 hours per week. The Phoenix works to involve users on a number of different levels with an aim to: enable patients and parents to take appropriate ownership of treatment and by encouraging their input into the multi-disciplinary team, to make treatment a collaborative process; to involve them in service developments; to monitor if services are being maintained and to identify gaps in treatment.

Service user involvement takes place on three main levels – firstly, on an individual daily basis revolving around regular meetings to discuss treatment plans; secondly, at a service monitoring level, which includes a *Patients Council* where patients meet with staff to discuss practical issues, and a *Parents Support Group*, with some patients and parents taking part in local training events, workshops and national conferences. Parents are also on the committee for planning the annual Phoenix Centre Conference. At the third level of involvement, that of service planning, an *Open Forum* is held on a termly basis between patients, parents and staff to get feedback on the service and proposals for development. The Phoenix also has a Newsletter to which past and present patients contribute and a website, set up following requests from service users.

Planning for the further development of user involvement at the Phoenix includes: developing evaluation questionnaires for all groupwork and exit interviews, gathering evaluation data from staff about how user involvement impacts on their work, and developing the website. Research is also under way looking at the effects on young people and parents of being involved in the work of the centre and its research activities.

Further information: Linda Dargie. Head of Patient and Parent Involvement. Tel: 01223 884 380. Email: Linda.dargie@cambsmh.nhs.uk

Peer support approaches

Interest in peer support approaches has accompanied the growing emphasis on user consultation and involvement and its use has been particularly evident in the education field. Whilst there is no commonly agreed definition, and with the term covering a range of activities, what 'peer support' broadly refers to is "using the knowledge, skills and experience of children and young people in a planned and structured way to understand, support, inform and help develop the skills, understanding, confidence and self-awareness of other children and young people with whom they have something in common."[35]
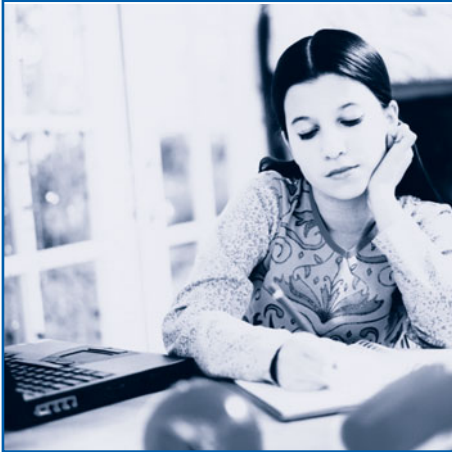
Peer support can take place between children and young people of different ages – cross-age or the same age – and can be approached in a number of different ways including:

- **Paired work** – for example, one-to-one listening or support. Peer mentoring is one particular form of this, often employed as a preventative strategy in which a mentor provides support to a mentee who may be facing a particular challenge (notable uses include the transition from primary to secondary school).

- **Informal** – such as befriending support.

- **Formal, collaborative group-work** – for example, with young people helping to run sessions for other young people.

- **Informal group-work** such as young people being involved in drop-in sessions.

Peer support can also take the form of **peer mediation** where young people are trained in defusing disagreements, conflicts or bullying amongst young people; **peer advocacy** when young people seek to identify and represent the views of other young people and **peer research**.

The benefits of peer support can be seen to echo many of the benefits attributed to user involvement more generally, most especially with regard to empowering young people and providing opportunities for the acquisition of knowledge and skills. They may also:

- Increase young people's willingness and ability to listen and take in information by presenting this in a different way.

- Provide a 'bridge' between young people and the professionals working with them.

Case study 8:
Forest House Unit, Young People's Information Leaflet

Forest House is a specialist psychiatric in-patient unit for adolescents in Hertfordshire. The unit is run by Hertfordshire Partnership Trust Children's Services Directorate and caters for up to 14 young people aged 13-16 years.

It was decided that the unit's information leaflet for young people needed to be updated and made more 'user-friendly'. Working alongside the CAMH Service Development Officer and the unit staff, the young people using Forest House developed a new template for a leaflet that contained all the information that they had wanted to know before being admitted. The leaflet covers everything from what clothes young people need, the daily routine, arrangements for seeing friends and going home at weekends.

Once the initial design was agreed, pictures were added to the leaflet and the young people designed the front cover using the Forest House camera. Young people and staff at Forest House approved the final draft and it is currently in the process of being printed. In the future, it is planned to give this leaflet to all young people attending welcome meetings, to help them to have all their questions answered before they are admitted.

Further information: Maria Nastri, CAMH Service Development Officer. Tel: 01707 280 774. Email: maria.nastri@hertscc.gov.uk

The following provides a checklist of some of the key things to consider in developing user involvement or participation in CAMHS. To assist practitioners, these issues have been divided up into a number of stages. However a key message is the **need for flexibility and responsiveness** and for ongoing review of the process, to ensure that it remains relevant to young people (and their parents/carers), addresses the issues of concern to them, offers them choice and is non-intimidating.

It is also important to find a balance between **content and process** – between engaging young people and being flexible but also, ensuring that you gather the information that you need.[23]
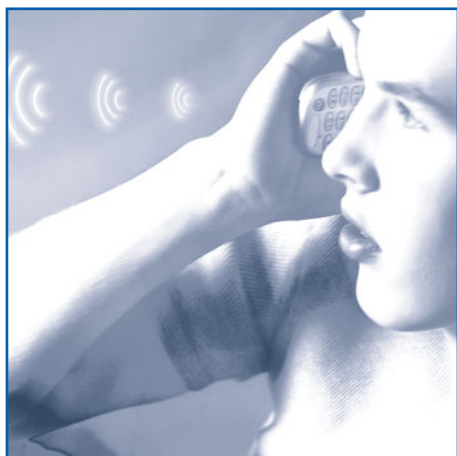
Stage 1: Issues to consider at the start

■ **Think about time requirements and availability of staff**

These considerations are relevant for both practitioners and commissioners since, right from the outset, an important thing to remember is that to develop involvement or participation properly (ie., not in a tokenistic 'tick box' fashion, but in a manner that truly allows young people and families to express their views) requires planning and thus staff time. Not allowing sufficient time, or having a poorly planned approach, can result in user frustration and disenchantment and can give the message that user involvement is not really a priority.

■ **What is the aim of developing user involvement/consultation?**

Are you planning a limited consultation exercise or ongoing user participation in actually shaping how your service operates now and in the future? Is it to be a regular event or a one-off? Are there particular issues that you wish to address? If you are seeking feedback, is this about satisfaction with the service, the outcome of the intervention, future plans for the service or a combination of one or more of these? Being clear with young people about your aims is important in order to avoid any misunderstandings about why their views are being sought.

Advice from Youth Access with regard to gathering feedback is that **it is better to do this for a specified time, in response to a particular question and then to let users know how you have responded and why, rather than continuously gathering data for its own sake.**[18]

■ **Where is your service in terms of the 'ladder of participation' model?**

Thinking about the decision-making processes and the existing opportunities for young people to be involved or to influence these is important in terms of deciding what is realistic for your service to aim towards. You will need to explain to young people (and parents/carers) what you are hoping to achieve. **Being honest about how much influence they might have, and how much you are able to take notice of what they say, is essential. Also remember:**

"Participation practice is often about increasing opportunities for children and young people to make decisions. This is about providing appropriate rather than limitless choice."[16]

Where there is a particular issue you wish to address, consideration of your service's usual planning cycle is also helpful in terms of considering the deadline for gathering information.

■ **Whom do you wish to consult or involve?**

Is the consultation with the individual child, the family or the wider community? Will you involve all young people using your service or just a representative sample? Will you only involve current users or those who used the service in the recent past as well? Do you want to target any particular groups (for example, those who are currently under-represented)? Will you need interpreters? Can young people bring a friend to any of the meetings? How will you access the young people (and parents/carers) you want to involve? A good starting point is to ask young people themselves about what they think of your ideas and whether they would like to get involved.[18] Working through established local community groups may be helpful in reaching 'hard-to-reach' groups.[19]

■ **Do you need to provide any training for young people?**

Depending on what you are aiming to do, you may need to provide some training for young people – for example, in presentation skills or chairing meetings. If you are thinking of involving young people in developing information about your service, some training or support in IT and/or design skills may be helpful – and a useful way of engaging young people in the process.

■ **Which staff will be involved?**

Whilst it is important that **all** staff are aware of and understand what is being planned to develop user involvement or participation, it is useful to think which staff might actually be directly involved and whether they require any training or help in gathering information about strategies or methods for consulting with young people or gathering feedback data. The use of **independent facilitators** from outside your service is another consideration.

■ Is any other consultation exercise/service evaluation or audit in progress?

Checking this out is important to avoid over-consultation of young people and their families/carers. It also allows you to build upon what is known and to avoid duplication.

■ Is ethics committee approval required?

This particularly applies if what you are proposing may involve clinical information about a young person and where young people may be helping in a systematic gathering of information. As a general rule, it is helpful to check out your plans for user involvement with your local ethics committee advisor who can advise on any paperwork that might be required. It is also important to plan ahead – if you do need approval from your local committee, this can take time to obtain (several months is not unusual, depending on how busy the committee is and when it meets).

Table 1: Potential barriers to participation

For young people:

■ Young people may feel intimidated by professionals and the language they use.

■ Young people may lack confidence and may not be given adequate information, support or training to be able to participate – and time to consider whether to become involved. A lack of time to build up trust in the professionals working with them is also significant.

■ Consultation 'fatigue' – being asked repeatedly but nothing actually changing.

■ Past experiences of not being listened to – disillusionment that this will be different.

■ Formal meetings may seem boring or complex, with only the adults making decisions.

For parents:

■ Caring responsibilities and practical problems (childcare, transport, time off work).

■ Fears of being seen as demanding or difficult which might jeopardise their child's care.

■ Being intimidated by formal settings or professional language.

Stage 2: Deciding your approach

■ Think about what will make young people want to become involved

What information might they (and their parents) need to feel confident in sharing their views? When would be the best time to involve them? (You need to consider what else is going on for them in terms of their illness, treatment, pressures from school, caring responsibilities at home.)

You also need to think about for how long you are asking people to become involved. **YoungMinds' experience suggests that it is very useful to give some indication of the likely time commitment required and that some young people may only want to be involved for a short, defined period.** Do you need incentives and if so, what should these be? Past experiences are also an important consideration:

"Young people who have had difficult life experiences are less likely to have the confidence and self-esteem to participate... If their views have not been taken into account in the past, they are less likely to be motivated to participate in the present."[3]

■ What information do you need to prepare?

This may include invitation letters and information sheets for both young people and for their parents/carers; consent forms (again for both young people and parents/carers); posters to display around your service.

If your approach is group/meeting based, you may want something explaining the 'ground rules' (not discussing information shared/young people's views outside the meeting, respecting different viewpoints and so on). Ideally young people should be involved in determining these matters.

It is important that all of these materials are age-appropriate and prepared in different languages as needed. You also need to consider sharing information verbally as well as providing written materials.

■ Do you have a policy on confidentiality/the sharing of information?

It is useful to have this written down and to give out/explain this information when first inviting young people (and families/carers) to become involved in your service.

■ What information gathering tools do you need?

Depending on the aims and scale of your user involvement activity, this might include designing interview or focus group schedules, semi-structured questionnaires or other self-complete forms. There is also growing interest in computer packages for young people to record their views or opinions. Will meetings be recorded or will someone take minutes? Will you need support for helping young people who are not confident or able to write down their views? Remember that there is no one 'right method' for involving young service users and that you need to think back to what your overall aim is, the young people you are working with and the 'fit' between the two.[36]

■ Making the sessions non-intimidating and addressing the balance of power

It is useful to think of 'warm-up' type activities or more creative ways of helping young people to express their views – for example, post-card or graffiti walls, use of video or art/drawing. **The learning from some of the YoungMinds consultations and research with young people is that activity-based approaches can be particularly useful in engaging with**

young people who may be quite reticent. Allowing young people (or parents/carers) to set the agenda, to work at their own pace, to raise any issues of their choice, to withdraw at any time and to be clear that there are no 'right' or 'wrong' answers are some of the techniques that can empower service users.[3]

■ What are the arrangements for providing support to young people?

Difficult issues may emerge from discussions with young people and it is important that you think through beforehand how young people can access support if they need this – ideally from a member of staff already known to them or a trusted adult. This is important to remember in terms of the venues you use and the availability of adults to offer support.

■ Practical matters

These include thinking about what space you have to meet with young people, refreshments (and the budget for these), materials such as flipcharts and pens and space for storing these. The recording of information gathered (how you will do this and where to keep the data) is especially important in terms of ensuring that young people's rights to confidentiality are protected.

Stage 3: Feedback and sustaining involvement

■ Will there be feedback and how will you arrange this?

How will those consulted know that they have been heard and be given opportunities to understand why decisions have been taken in the way that they have?

"Feedback to young people is an important and integral part of dialogue, not an afterthought. Adequate feedback includes information about how views have (or have not) been taken forward..."[16]

■ Maintaining interest

This links to the points made earlier about young people feeling that their views are valued and being taken seriously, that they understand the extent to which they might influence change – and crucially, that if change is not possible, time is given to explaining why. Providing updates on any progress – and looking for new and creative ways to allow young service users to express their views and suggestions – perhaps through a newsletter – are other important things to remember.

■ The importance of participation as a process

In many services, including health, a major limitation in past activities has been the tendency for user consultation or participation to be done on an ad hoc, one-off basis – this can seem tokenistic when people keep being asked for their views but with no change then taking place. Another weakness has been the focus on gathering retrospective user views about services when, in effect, it is too late to allow users to be involved in the planning of services.

A key message from the literature is that it (participation, consultation or involvement) should **not** be seen as:

"an add-on to the business of providing services; it is to be built in to planning cycles as an integral part of the function of effectively meeting people's needs."[17]

It is also crucial that there is organisational commitment and collaboration between agencies in order to develop a strategy for participation.

Table 2: Barriers facing staff in developing user participation

- ■ A lack of appropriate skills and experience.
- ■ A lack of time, resources and support for staff – other service priorities and pressures.
- ■ A lack of training in participation techniques and the use of communication tools.

"Offering choice in a meaningful way can be time-consuming and can sit uncomfortably with the pressures and demands driving the consulting agency's agenda... it is crucial to acknowledge and debate these conflicts as they occur, as they constitute the process of forging an agency culture which can accommodate user views."[37]
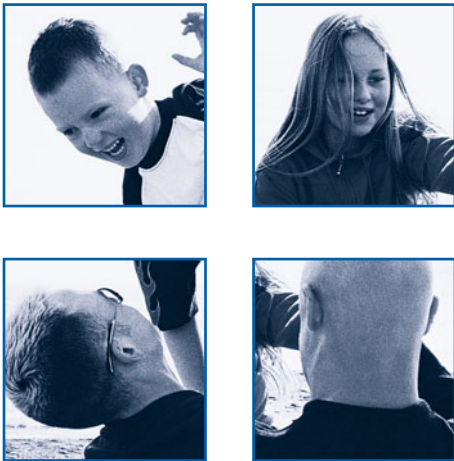
Advantages and disadvantages of different ways of gathering information from young people and families/carers

The following draws upon Mumby's work for Youth Access *Building user involvement* (2001)[18] and Lightfoot and Sloper's guideline for involving young patients in health services development, *Having a say in health* (2002).[36]

Advantages

Suggestions box	Easy to set up; anonymous; does not cost much.
Self-complete questionnaires	Less time consuming and cheaper than interviews; complete in own time; anonymity; can reach a large sample or those who would find it difficult to travel. Good for routine collection of data.
Questionnaires with drawings/cartoons	Easy to complete; gets around language problems; gives immediate picture of satisfaction levels.
Computer packages	Choice and variety; easily personalised; easy to repeat instructions; good for including young people with learning and other difficulties; allows data collection in a form that facilitates immediate analysis.
Telephone interviews	Do not need dedicated space; good at picking up extra information; use of an independent person can protect anonymity and encourage views to be shared. Young people can ask questions.
Face-to-face interviews	High response rates; good for young people with low literacy skills or who dislike forms. Young people can ask questions. More reliable than groups for finding out individual views.
Peer interviews/research	Direct insight into the issues; young people can learn through the experience; less threatening. Rigorous research can make findings more credible to others.
Focus groups	Different viewpoints can come together; young people may be encouraged to speak out by hearing other young people's views; can be informal; good for those with literacy problems.
Users on committees and planning groups	Allows young people to have more influence with regard to specific services; can increase sense of ownership; prepares young people for participating in adult society; informs the understanding and decision-making of the adults on the committee or group.
Users involved in service evaluation	Young people learn more about the area and views of other people; provides skills for young people and experience of team working. Builds a shared commitment to act on the findings of the evaluation.
Users in charge of changes	Young people can have new and enthusiastic ideas; gives service credibility; young people can experience delivery and management of services and can become role-models for other young people. They may also become more prepared to challenge existing arrangements.

Disdvantages

Easily forgotten; not good for those with literacy problems.

Low response rates; questions may be misunderstood; not easy to clarify; not good for users with language, reading or writing limitations. Can seem cold and faceless – at odds with involving young people.

Can only give a limited amount of information; can be hard to interpret.

Fears about confidentiality; need access to computers; not all young people (or parents/carers) computer literate; some prefer face-to-face contact.

Fears about confidentiality; poor quality data if people called when they are busy or preoccupied; can be hard to access people.

Young people may feel obliged to respond – or unable to challenge the interviewer. Can be costly in terms of staff skills and time needed.

High time and training demands; tendency for high drop out numbers; it must not be assumed that peer researchers represent all young people.

Can be difficult to arrange; you are limited in the number of views you can gather; need to make sure one or two do not dominate the meeting; can be hard to be representative. Needs work to maintain attendance. Size – ideally six or less which allows young people to get to know one another.

Young people may be seen as a 'token' presence; only certain young people may feel confident enough to take part in this way; support needs can be heavy and time-consuming.

May be seen as less objective in that the evaluation is being carried out by young people who may have a vested interest in the service. Time-consuming to identify, involve and support young people.

Maintaining boundaries can be difficult; young people running a service can start to be seen as different and thus unrepresentative; it may be hard for them to sustain involvement due to other commitments and transitions they are going through.
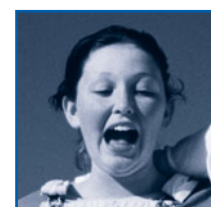
Resources for practitioners: selected literature and other materials

■ **What is meant by participation, involvement and consultation?**

Ahmad, Y., Dalrymple, J., Daum, M., *et al*. (2003). *Listening to children and young people 2003*.
Bristol: University of the West of England.
See http://www.southglos.gov.uk/NR/rdonlyres/CEFF2851-83FC-4D0C-BF13-5970C3226C2D/0/ListeningtoChildrenQ.pdf

Kirby, P., Lanyon, C., Cronin, K., *et al*. (2003). *Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation*. London: Department for Education and Skills.
See http://www.dfes.gov.uk/childrenstrusts/supportfortrusts/buipartresearch.pdf

Sinclair, R. (2004). Participation in practice: making it meaningful, effective and sustainable. *Children and Society (Special Issue on Children, Young People and Participation)*, **18** (2), pp. 106-108.
For more information visit: http://www3.interscience.wiley.com/cgi-bin/jhome/4805

■ **Policy and legal context of participatory practice**

Alderson, P. & Montgomergy, J. (1996). *Health care choices: making decisions with children*. London: Institute for Public Policy Research (IPPR). For more information visit: http://www.ippr.org.uk/publicationsandreports/

Children and Young People's Unit (2001). *Learning to listen: core principles for the involvement of children and young people*. London: Department for Education and Skills.
See http://www.everychildmatters.gov.uk/_files/1F85704C1D67D71E30186FEBCEDED6D6.pdf

Contact a Family & The Council for Disabled Children (2004). *Parent participation: improving services for disabled children*. London: Contact a Family. Two versions of this document are available, one for parents and one for professionals.
For more information visit: http://www.cafamily.org.uk/ParentParticipationFlyer.pdf

Department for Education and Skills (2004). *Getting the best from complaints: consultation on the changes to social services complaints procedures for children, young people and other people making a complaint*. London: Department for Education and Skills.
See http://www.dfes.gov.uk/consultations/downloadableDocs/Getting%20the%20Best%20from%20Complaints.pdf

Department for Education and Skills (2004). *Working together: giving children and young people a say*. London: Department for Education and Skills. See http://publications.teachernet.gov.uk/eOrderingDownload/DfES-0134-2004.doc

Department of Health (2002). *National standards for the provision of children's advocacy services*. London: Department of Health.
See http://www.dh.gov.uk/assetRoot/04/01/88/93/04018893.pdf

Department of Health & Department for Education and Skills (2004). *Core standards: National Service Framework for children, young people, and maternity services*. London: Department of Health. See http://www.dh.gov.uk/assetRoot/04/08/92/20/04089220.pdf

Health Development Agency (2004). *Promoting children and young people's participation through the National Healthy School Standard*. London: Health Development Agency. See http://www.wiredforhealth.gov.uk/PDF/NHSS_participation_briefing.pdf

■ Benefits and demands of participation (including peer support)

Donnelly, E. (2003). *Consulting children and young people in Liverpool*. Liverpool: NSPCC & Liverpool Children's Fund. Available from John Hogan, Liverpool Children's Fund, 1-7 Seymour Terrace, West Derby Road, Liverpool L6 1AE.

Farrell, C. (2004). *Patient and public involvement in health: the evidence for policy implementation*. London: Department of Health. See http://www.dh.gov.uk/assetRoot/04/08/23/34/04082334.pdf

Harnett, R. (2003). Peer advocacy for children and young people. *Highlight*, **202**.
More information available at http://www.ncb.org.uk/resources/res_detail.asp?id=468
or contact the NCB Library Tel: 020 7843 6000.

Hartley-Brewer, E. (2002). *Stepping forward. Working together through peer support.* London: National Children's Bureau.

Hedges, C. & McKeown, C. (2000). *Give us a voice: consultation and participation in child and adolescent mental health services within the Trent region*. Newcastle: Save the Children. Available from Save the Children, Newcastle. Tel: 0191 222 1816.

Mumby, C. (2001). *Building user involvement: a step-by-step guide to involving users in youth information, advice, counselling and support services.* London: Youth Access. Order online at: http://www.youthaccess.org.uk/publications/

■ Young people's views about CAMHS/health services

Armstrong, C., Hill, M. & Secker, J. (1998). *Listening to children*. London: Mental Health Foundation.
See http://mhf.org.uk/html/content/listening_to_children.pdf

Gibson, R. & Possamai, A. (2002). What young people think about CAMHS. *Clinical Psychology*, **18** (October), pp. 20-24.

Laws, S. (1998). *Hear me! Consulting with young people on mental health services*. London: Mental Health Foundation.
See http://www.mhf.org.uk/html/content/hear_me.pdf

McArthur, L. (2004). *Listening to children and young people: the Alder Hey Consultation*. Liverpool: Alder Hey Hospital & The Children's Society. See http://www.alderhey.com/RLCH/assets/Listening%20to%20Children%20book.pdf

Public Health Institute of Scotland (2003). *Needs assessment report on child and adolescent mental health consulting children, young people and parents*. Glasgow: Public Health Institute of Scotland.
See http://www.phis.org.uk/pdf.pl?file=publications/CAMH2.pdf

Street, C. (2004). Mental health services: what children and young people want. *Highlight*, **210**.
More information available at http://www.ncb.org.uk/resources/res_detail.asp?id=662 or contact the NCB Library
Tel: 020 7843 6000.

Street, C. & Svanberg, J. (2003). *Where Next? New directions in in-patient mental health services for young people. Report 1. Different models of provision for young people: facts and figures.* London: YoungMinds. For more information visit: http://www.youngminds.org.uk/publications/researchreports/wherenext.php

Resources for practitioners: selected literature and other materials (cont.)

■ **Toolkits, participation guides and guidelines for consultation**

Advocacy in Somerset (In Press). *Headspace Toolkit*. Taunton: Advocacy in Somerset.
For more information visit: http://www.headspacetoolkit.org or contact Advocacy in Somerset, 3 Quadrant Court, Middle Street, Taunton, Somerset TA1 1SJ. Tel: 01823 324 762; email: headspace.toolkit@virgin.net

Alderson, P. & Montgomergy, J. (1996). *Health care choices: making decisions with children*. London: Institute for Public Policy Research (IPPR). For more information visit: http://www.ippr.org.uk/publicationsandreports/

Children's Rights Alliance for England (CRAE) (2005). *Ready Steady Change*. See http://www.crae.org.uk/rsc/latest.html

Department of Health (2003). *Strengthening accountability: involving patients and the public. Practice guidance*. London: Department of Health. See http://www.doh.gov.uk/involvingpatients/index.htm

Fajerman, L., Jarrett, M. & Sutton, F. (2000). *Children as partners in planning: a training resource to support consultation with children*. London: Save the Children. For more information visit: http://www.savethechildren.org.uk/publications

Fajerman, L., Treseder, P. & Connor, J. (2004). *Children are service users too: a guide for consulting children and young people*. London: Save the Children. For more information visit: http://www.savethechildren.org.uk/publications

Ferns, P. (In Press). *A holistic approach to Black and minority ethnic mental health: the Letting Through Light training pack*. Brighton: Pavilion Publishing. For further information visit: http://www.pavpub.com
(NB: Based on work with adult service users – however provides discussion of the issues influencing the engagement of Black and minority ethnic groups.)

Hanley, B., Bradburn, J., Barnes, M., *et al.* (2004). *Involving the public in NHS, public health and social care research: briefing notes for researchers*. Eastleigh, Hants: INVOLVE. See http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf

Kirby, P. (2004). *A guide to actively involving young people in research: for researchers, research commissioners and managers*. Eastleigh, Hants: INVOLVE. See http://www.invo.org.uk/pdfs/Involving_Young_People_in_Research_151104_FINAL.pdf

Leeds CAMHS & Barnardo's. (Work in Progress). *Leeds CAMHS participation user/carer project*. See http://www.ru-ok.com/leeds.html

Lightfoot, J. & Sloper, P. (2002). *Having a say in health: guidelines for involving young patients in health service development*. York: Social Policy Research Unit, University of York. See http://www.york.ac.uk/inst/spru/pubs/pdf/havsayhe.pdf

Melia, J. (2005). *Wavelength: a handbook of communication strategies for working with young people*. Brighton: Trust for the Study of Adolescence. For more information visit: http://www.tsa.uk.com or Tel: 01273 693 311.

Mumby, C. (2001). *Building user involvement: a step-by-step guide to involving users in youth information, advice, counselling and support services*. London: Youth Access. For more information visit: http://www.youthaccess.org.uk/publications/

National Youth Agency (2003). *Involving children and young people: where to find out more*. London: Department for Education and Skills. See http://www.dfes.gov.uk/listeningtolearn/downloads/PGSResources.pdf

Royal College of Paediatrics and Child Health & Barnardo's (2001). *Accessible leaflets on health for children, young people and their carers*. London: Barnardo's.

Wright, P., Haydon, D., Morgan, C., et al. (2002). *Taking Part Toolkit: promoting the 'real' participation of children and young people*. Manchester: Northwest Children's Taskforce. The pack consists of four different documents: Participation Report, Resource Pack, Standards and Audit Tool. The Toolkit costs £27 and is available from Kall Kwik, based in Manchester. Tel 0161 876 5111 or email: sales@kallkwiksq.com

APPENDIX 1:

Core Principles for the Involvement of Children and Young People (Children and Young People's Unit 2001)

A visible commitment is made to involving children and young people, underpinned by appropriate resources to build a capacity to implement policies of participation.

- There is visible commitment to the principle and practice from managers and senior management teams.

- Participation is built into the department or agency values and is reflected in strategic planning, delivery, resourcing, communication and business improvement activities.

- Opportunities are provided to enable relevant staff to develop the skills and attitudes to engage effectively with children and young people.

Children and young people's involvement is valued.

- Children and young people are treated honestly. That means that their expectations are managed and that they are helped to understand any practical, legal or political boundaries of their involvement.

- The contributions of children and young people proportionate to their age and maturity, are taken seriously and acted upon, and feedback from children and young people confirms this.

- Feedback on the impact of children and young people's involvement is timely and clear.

Children and young people have equal opportunity to get involved.

- Children and young people are not discriminated against or prevented from participating effectively on grounds of race, religion, culture, disability, age, ethnic origin, language or the area in which they live.

- Departments and agencies take a proactive approach in targeting those facing greatest barriers to getting involved (for example, younger children, children and young people from minority ethnic backgrounds, those living in rural areas or disadvantaged neighbourhoods, children missing school, young people in the youth justice system, refugees, traveller children, disabled and other children with special needs or special personal or family

circumstances) to ensure that they are aware and take up appropriate opportunities to have their say.

- Where necessary support and opportunities for training and development are provided to children and young people so that they can contribute effectively.

- Relevant information is available to children and young people in good time and in appropriate formats, is jargon free, culturally appropriate and accessible.

Policies and standards for the participation of children and young people are provided, evaluated and continuously improved.

- The rationale and success criteria against which progress will be measured are set out from the start.

- Children and young people are involved in reviewing the lessons learnt.

- Departments and agencies agree quality standards and codes of conduct for working with children and young people, and set out how confidentiality and child protection issues will be handled.

REFERENCES

1   Children and Young People's Unit (2001). *Learning to listen: core principles for the involvement of children and young people*. Page 2. London: Department for Education and Skills. See http://www.everychildmatters.gov.uk/_files/1F85704C1D67D71E30186FEBCEDED6D6.pdf

2   Farrell, C. (2004). *Patient and public involvement in health: the evidence for policy implementation*. Page 2. London: Department of Health. See http://www.dh.gov.uk/assetRoot/04/08/23/34/04082334.pdf

3   Wright, P., Haydon, D., Morgan, C., et al. (2002). *Taking Part Toolkit: promoting the 'real' participation of children and young people. Participation report*. Pages 14 and 53. Manchester: Northwest Children's Taskforce.

4   *Health and Social Care Act 2001* (2001). London: The Stationery Office. See http://www.opsi.gov.uk/acts/acts2001/20010015.htm

5   *Education Act 2002* (2002). London: The Stationery Office. See http://www.opsi.gov.uk/acts/acts2002/20020032.htm

6   *Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995* (2001). London: The Stationery Office. See http://www.bristol-inquiry.org.uk/index.htm

7   Department for Education and Skills (2004). *Working together: giving children and young people a say*. London: Department for Education and Skills. See http://publications.teachernet.gov.uk/eOrderingDownload/DfES-0134-2004.doc

8   *Children Act 2004* (2004). London: The Stationery Office. See http://www.opsi.gov.uk/acts/acts2004/20040031.htm

9   University of East Anglia (2005). *Children's trusts: developing integrated services for children in England*. London: Department for Education and Skills. See http://www.dfes.gov.uk/research/data/uploadfiles/RR617.pdf

10 Badham, B. & Wade, H. (2005). *Hear by right: standards for the active involvement of children and young people (Revised Edition)*. Leicester: National Youth Agency. See http://www.nya.org.uk/hearbyright/design/filelibrary/3.%20HBR%20the%20book%202005.pdf

11 Department of Health (2002). *Improvement, expansion and reform: the next 3 years. Priorities and planning framework 2003-2006*. London: Department of Health. See http://www.dh.gov.uk/assetRoot/04/07/02/02/04070202.pdf

12 Commission for Social Care Inspection (2005). *Getting the best from complaints – the children's view: what children and young people think about the government's proposals to change the Social Services complaints procedures*. London: Commission for Social Care Inspection. See http://www.csci.org.uk/publications/childrens_rights_director_reports/getting_the_best_from+_complaints_childrens_views.pdf

13 *UN Convention on the Rights of the Child* (1989). See http://www.unhchr.ch/html/menu3/b/k2crc.htm

14 Fajerman, L., Treseder, P. & Connor, J. (2004). *Children are service users too: a guide for consulting children and young people*. Page 9. London: Save the Children.

15 Bell, B. (2004). *Practice standards in children's participation*. London: Save the Children.

16 Kirby, P., Lanyon, C., Cronin, K., *et al.* (2003). *Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation*. Pages 21 and 9. London: Department for Education and Skills. See http://www.dfes.gov.uk/childrenstrusts/supportfortrusts/buipartresearch.pdf

17 Hedges, C. & McKeown, C. (2000). *Give us a voice: consultation and participation in child and adolescent mental health services within the Trent region*. Pages 23, 16 and 20. Newcastle: Save the Children.

18 Mumby, C. (2001). *Building user involvement: a step-by-step guide to involving users in youth information, advice, counselling and support services*. London: Youth Access.

19 Contact a Family & Council for Disabled Children (2004). *Parent participation: improving services for disabled children. Parents' guide*. Page 11. London: Contact a Family. See http://www.cafamily.org.uk/ParentParticipationFlyer.pdf

20 Kurtz, Z. & James, C. (In Press). *What's new: learning from the CAMHS Innovation Projects*. Page 7 of Executive Summary. London: Department of Health & Department for Education and Skills. Executive summary available at: http://www.dh.gov.uk/assetRoot/04/01/50/51/04015051.pdf

21 Street, C. & Svanberg, J. (2003). *Where Next? New directions in in-patient mental health services for young people. Report 1. Different models of provision for young people: facts and figures*. London: YoungMinds.

22 Street, C., Stapelkamp, C., Taylor, E., *et al.* (2005). *Minority Voices: research into the access and acceptability of services for the mental health of young people from Black and minority ethnic groups*. London: YoungMinds. See http://www.youngminds.org.uk/publications/researchreports/minorityvoices.php

23 Laws, S. (1999). Involving children and young people in the monitoring and evaluation of mental health services. *Healthy Minds* (6), pp. 3-5. See http://www.mhf.org.uk/html/content/hear_me.pdf

24 Alderson, P. & Montgomergy, J. (1996). *Health care choices: making decisions with children*. London: Institute for Public Policy Research (IPPR).

25 Health Development Agency (2004). *Promoting children and young people's participation through the National Healthy School Standard*. Page 15. London: Health Development Agency. See http://www.wiredforhealth.gov.uk/PDF/NHSS_participation_briefing.pdf

26 Armstrong, C., Hill, M. & Secker, J. (1998). *Listening to children*. London: Mental Health Foundation. See http://mhf.org.uk/html/content/listening_to_children.pdf

27 Steel, R. (ed.) (2004). *Involving the public in NHS, public health, and social care research: briefing notes for researchers. 2nd Edition*. Eastleigh, Hants: INVOLVE. See http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf

28 Kirby, P. (1999). *Involving young researchers: how to enable young people to design and conduct research*. York: York Publishing Services.

29 Claveirole, A. (2004). Listening to young voices: challenges of research with adolescent mental health service users. *Journal of Psychiatric & Mental Health Nursing*, **11** (3), pp. 253-260.

30 Paul, M. (2004). Decision-making about children's mental health care: ethical challenges. *Advances in Psychiatric Treatment*, **10** (4), pp. 301-311.

31 Kurtz, Z., Stapelkamp, C., Taylor, E., et al. (2005). *Minority voices: a guide to good practice in planning and providing services for the mental health of Black and minority ethnic young people*. London: YoungMinds. See http://www.youngminds.org.uk/minorityvoices/materials.php

32 Advocacy in Somerset (2005). *Headspace Toolkit*. Taunton: Advocacy in Somerset. See http://www.headspacetoolkit.org

33 Children's Rights Alliance for England (CRAE) (2005). *Ready Steady Change*. See http://www.crae.org.uk/rsc/latest.html

34 Department of Health (2002). *National standards for the provision of children's advocacy services*. Page 1. London: Department of Health. See http://www.dh.gov.uk/assetRoot/04/01/88/93/04018893.pdf

35 Hartley-Brewer, E. (2002). *Stepping forward. Working together through peer support*. Page 3. London: National Children's Bureau.

36 Lightfoot, J. & Sloper, P. (2002). *Having a say in health: guidelines for involving young patients in health service development*. York: Social Policy Research Unit, University of York. See http://www.york.ac.uk/inst/spru/pubs/pdf/havsayhe.pdf

37 Ahmad, Y., Dalrymple, J., Daum, M., et al. (2003). *Listening to children and young people 2003*. Page vii. Bristol: University of the West of England. See http://www.southglos.gov.uk/NR/rdonlyres/CEFF2851-83FC-4D0C-BF13-5970C3226C2D/0/ListeningtoChildrenQ.pdf

Children's and young people's participation is at the centre of the government's Every Child Matters: Change for Children programme and the delivery of the National Service Framework.

This guide has been written by YoungMinds, the national children's charity which promotes the emotional well-being and mental health of all children and young people. The publication is intended to provide practical information that staff in specialist Child and Adolescent Mental Health Services (CAMHS) and their colleagues in all services that work to promote the mental health and well-being of children and young people – in other words, 'comprehensive' CAMHS – can develop to suit their own requirements.

The guide draws on the experience of YoungMinds' researchers and consultants working with children and young people in many different services from across the UK. It provides an overview of participation practice from a range of sources including social care, child mental health, education, youth services and services for children with disabilities. Case studies are used throughout to illustrate examples of ways of involving children and young people in service development and in individual decision making.

YoungMinds
for children's mental health