

*Turning what young people say
into what services do*

Children and young people's participation in CAMHS

A literature review for informed practice

**Health and Social Care Advisory Service
(HASCAS)**

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The United Nations General Assembly has pledged to build
a world fit for children.

Participation can be seen as a commitment to build
services and supports that are fit for children.

1. Rationale: background to this paper

Introduction

This literature review for informed practice is part of the HASCAS project, *Turning what young people say into what services do*, which has been funded by the Department of Health. The explicit purpose is to provide, in one document, a synthesis of the key publications, both peer reviewed and “grey” literature, around young people’s participation in children’s services, with a particular emphasis on child and adolescent mental health services (CAMHS). A number of similar documents, most of which are cited here, have already provided an overview of children’s participation, alongside models and frameworks for participation and practice guidelines and standards. Some of these have addressed child and adolescent mental health specifically and these are highlighted in the references section for ease of access. The intention here is to draw together the findings from these documents, to provide an accessible reference point for any individual or organisation wishing to begin participation work, improve what they already do, or check their practice against a benchmark.

There are two companion documents to accompany this review, the first is an *Interactive Annotated Bibliography*, in which the key literature has been listed and summarised, with full references and internet access (where available). Secondly a set of *Quality standards for children and young people’s participation in CAMHS* has been adapted from a well established framework (National Youth Agency (Badham and Wade, 2006).

Throughout this document significant items, including quotes from major reports and policy, have been isolated clearly from the main text, in different sized fonts or presented in boxes. This is to enable readers to cut and paste freely in order to support the production of local strategies and plans for participation.

Context

Implementing user participation in child and adolescent mental health services presents challenges and these may be a reason why user involvement has on the one hand been high on the agenda of CAMHS “must-dos” whilst making quite slow progress across services in England (Rees, 2007). Potential conflicts of interest arise out of the holistic nature of most approaches in CAMHS, in which users of services can include parents, carers and other family members, those with corporate or statutory responsibility for the child’s welfare, as well as the referred child or young person. Each of these individuals and units may have different perspectives and diverse interests (Wolpert et al, 2001, p.5).

Fajerman et al (2004) have noted from their research and practice review that across public services policy, practice and research have been at different stages.

They identify the risk that participation will become the latest 'buzzword' and 'tick box' exercise before organisations can embed participation fully within their culture, structure, practice and review.

There is a remarkable consistency across a range of literature, whether local, national, or international, about what young people want from services and how they would like to be involved in shaping them. A stated aim of *Turning what young people say into what services do* is that professionals stop at just asking young people what they want and focus instead on, first, making plans to change provision so that it reflects what we already know about young people's wishes and second, involving young people themselves in those changes.

CAMHS focus

Most of what is reviewed in this document is applicable to children and young people in any context, albeit that there is a focus on CAMHS. A working definition of CAMHS often proves problematic, as, in one sense any service that provides in any way for the mental health and emotional well being of children and young people may be seen as part of CAMHS. In the language of the *National Service Framework for Children, Young People and Maternity Services* (NSF), based on the earlier publication by NHS Health Advisory Service (1995), these services span the four tiers of CAMHS provision. At tier 1, meeting low level need, are the providers of primary care across health, social care and the voluntary sector. At tier 2, a service is offered to those with mild to moderate need, either by mental health specialists supporting and training tier 1 staff, or by the tier 2 practitioners providing brief interventions. Specialist services, normally comprising multidisciplinary team working, are offered at tier 3 for severe and complex need and tier 4 at the highly specialised end, involves in-patient care and intensive treatments.

Whilst the tiered framework has been adopted widely over the past decade, the advent of over-arching children's policy in *Every Child Matters* (ECM) has provided a fresh approach to conceptualising children's services, of which CAMHS is viewed as a component. ECM introduced the idea of three levels of children's services, universal services are those available to every child, targeted services are those provided for specific groups, who may be at risk or in need and specialist services are for those children and young people with severe and complex needs.

Summary 1

Purpose of this document

It is an easily accessible report in which readers can locate the evidence to enable them to be clear about what participation is, why, how and when to do it and who will benefit. for child and adolescent mental health services to:

Why it has been produced

There is a growing number of literature reviews in this field, but this differs by being offered as one of three tools to promote and support informed practice. It has a focus on CAMHS, encompasses a breadth of literature and encourages readers to take action.

Using the document

Cut and paste freely, remembering to acknowledge sources. Also refer to the annotated bibliography and quality standards.

CAMHS focus

CAMHS refers to any service or support that promotes the mental health and emotional wellbeing of children and young people. This includes universal services (Tier 1), targeted and specialist services (Tiers 2 and 3) and highly specialised intensive provision (Tier 4).

2. Meanings: what is understood by children and young people's participation.

Children and young people

Following the UN Convention on the Rights of the Child, a child means every human being below the age of eighteen years. It is common practice in the UK however to differentiate between younger children and teenagers by referring to the latter as young people, so most of the literature refers to "children and young people". Some literature is focused specifically on the older age group and may refer to young people in "the second decade of life" (Commonwealth Secretariat, 2005) as adolescents. Literature from the UK, in which the young person's perspective is represented, tends to eschew the word adolescent, as young people themselves may regard the term as technical or clinical.

Participation

There is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process.

(Arnstein, 1969)

"Participation is exchanging information and ideas with others"

"Participation is contributing to an action"

"Participation is making it easier for people to understand each other and become interested in what each does."

"...to become a doer instead of just a hearer"

(Young people's views, Commonwealth Secretariat, 2005a)

The terms involvement and participation are sometimes used interchangeably, but arguably participation should be preferred as it is the active verb, whereas involvement is the passive. Street and Herts (2007) differentiate as follows:

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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.

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.

This view of participation echoes a *Save the Children UK* report, (Fajerman, et al, 2004), which states that participation is about influencing decision-making and achieving change and, importantly, that children's participation is a value that cuts across all programmes and takes place in all arenas – from homes to government and from local to international levels. Levels of participation is a theme identified by the Children and Young People's Unit (2001)ⁱ, offering three domains of decision making in which young people may participate: individual, local and national. Individual decisions are about children's own lives, for example as users of health, education and social care services. In CAMHS this would include being active participants in planning their care. Local decision making may involve children in the design and provision of play facilities, leisure, transport and guidance services. At a national level children might be involved in developing or evaluating policy and guidance.

Participation has been described as a multi-layered concept, in which the same term may be used to describe very different processes. Kirby, et al, (2003, p.4) offer six dimensions of participation, which are the:

- level of participation;
- focus of decision-making;
- content of decision-making;
- nature of participation activity;
- frequency and duration of participation;
- children and young people involved.

What is clear from all the literature reviewed is that participation should not be confused with consultation, which can have many meanings, from adult-led activities that simply seek children's opinions, to processes that foster child-initiated and child-driven approaches. As Street and Herts (2007) point out, consultation is often equated with participation – but crucially it is usually adults who hold the power to decide what to do with the information. Spicer and Evans (2005) discriminate between approaches that serve adults' and/or professionals' policy-driven agendas and those with the potential to bring about greater degrees of empowerment to children as individuals. They assert that the former approach offers limited personal benefits to those participating, whilst the latter can exclude children from diverse backgrounds.

Summary 2

Referring to children and young people

Some documents refer to anyone under 18 as a child, whilst others differentiate between children, up to the age of 12 or 13 and young people aged 13-18. Some documents refer to young people as adolescents.

Consultation, involvement and participation

Consultation is led by (adult) professionals, trying to elicit feedback and ideas about services. The agenda for involvement is also set by (adult) professionals, but children and young people may be able to influence decisions. Participation is an equitable relationship between adult professionals and children and young people, in which they work together, in some cases with the young people leading.

Levels of participation

Children and young people may participate on an individual level, around services and supports they use, on a local level, around the provision of services and supports close to where they live and on a national level around more general policy and strategy. Importantly participation means children and young people having influence on developments outside their own immediate sphere.

3. Underlying principles: why children and young people's participation is necessary.

Global framework

In 1989 the United Nations adopted a human rights treaty for children, known as the UN Convention on the Rights of the Child (UNCRC). UNCRC covers all children aged 17 (up to 18th birthday) or under and gives children a set of economic, social, cultural, and civil and political rights. The UK ratified UNCRC in December 1991.

UNCRC is UNICEF's guiding frame of reference, and provides a legal foundation for the ethical and moral principles that guide the organisation's work for and with children. UNICEF's human rights based approach to programming for and with children is therefore informed by this legal framework. This framework is enforced and legitimised by the United Nations Declaration of Human Rights.

The sections of UNCRC that pertain to children and young people's participation are given in Box 1 below:

Box 1. UNCRC, sections pertaining to participation

Article 2	requires all the rights in the CRC to be implemented for every child, without discrimination
Article 12	grants all children the right to express their views, and to have these views given due weight in all matters that affect them
Article 13	gives every child the right to freedom of expression – so long as they respect the rights of others
Article 17	gives children the right to receive, seek and give information
Article 23	gives disabled children the right to active participation in their community

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July 2002 saw UNICEF's commissioning of the Commonwealth Youth Programme to prepare a toolkit on promoting meaningful children's and young people's participation, based on the lessons learnt by UNICEF programmes in countries around the world.

Where adolescents are concerned, attention is often paid to the individual's problems. By contrast, development is about paying attention to whole human beings, whole families and whole communities

Where a programme's approach is guided only by problem-solving and excludes the assets of adolescents, fragmented responses to adolescents' needs are the end result. This often leads for example, to separate projects on HIV/AIDS, drugs and literacy. Problems that are easiest to see tend to get more attention and resources, while important but less visible needs are neglected.

Where adolescents do not have opportunities to participate, they do not get the chance to develop their knowledge, skills and maturity.

Adolescents' well-being is best achieved by strengthening their capabilities and enlarging their access to opportunities.

Commonwealth Secretariat (2003: p.12)

National context

Whilst there is no specific domestic law that makes it statutory for national and regional bodies to consult with children and young people on all matters that affect them, certain children in particular situations do have some legal participation rights, see Box 2.

Box 2. Legal framework

One of the five outcomes of children's well-being, enshrined in the Children Act 2004, is 'making a positive contribution'. The Children Act 1989 requires that social workers always consult a child or young person who is in care, or who might come into care, before making any decision about them. The Children Act 2004 amended this Act so that now children involved in child protection inquiries or children in need assessments must be consulted.

The Children Act 1989 requires that, in family law proceedings, the court must consider the child's wishes and feelings. Regulations passed by Parliament in 2003 allow children and young people to become 'associate members' of a committee of a school governing body

Section 7 of the Education Act 2005 requires Ofstedⁱⁱ to have regard to the views of school students, as well as other stakeholders, when carrying out school inspections.

The Youth Matters agenda will considerably increase young people's opportunities to contribute to decision-making in local communities.

Section 3 of the Child Care Act 2006 says that local authorities must have regard to the views of young children where relevant and available.

The Disability Discrimination Act requires local authorities to encourage the participation of disabled people in public life.

Additionally, best practice guidance is outlined in national policy, specifically within Standard 3 of the National Service Framework for Children, young people and maternity services (Department of Health, 2004) where the vision is articulated as:

- Professionals communicating directly with children and young people, listening to them and attempting to see the world through their eyes.
- Children, young people and their families having equitable access to high quality, child-centred health promotion, prevention and care services, which are responsive to their individual developing needs and preferences.
- The views of children, young people and families being valued and taken into account in the planning, delivery and evaluation of services.

The Children's Commissioner for England was appointed in March 2005. The over-arching function of the children's commissioner is to promote awareness of the views and interests of children in England. It is also required that the children's commissioner will encourage persons and organisations engaged in activities affecting children to take account of their views and interests, with regard to the United Nations Convention on the Rights of the Child.

The Commissioning framework for health and well-being (Department of Health, 2007, p. 20) describes key outcomes of, and requirements for, good local commissioning, including those that relate specifically to participation:

Commissioners should empower individuals to influence services and voice their concerns, recognising that some people can find it very difficult to make their voice heard when services are inadequate, or when something goes wrong. They can do this by:

- making it easy for users and patients to provide feedback on services, including how they could be improved, and identifying perceived gaps in provision
- developing mechanisms for patients and service users, as well as the general public, to get involved in shaping commissioning priorities and services. Effective community engagement is achieved through a variety of techniques: surveys, focus groups, large group events and newer approaches, such as blogs and internet discussion groups.

Commissioners should also focus on those whose voice is not often heard (such as children and young people, socially excluded people, asylum-seekers) and use a variety of engagement, equity audit or social marketing approaches to ensure that they are able to have their views and needs recognised, by:

- ensuring that there are effective advocacy services and complaints procedures in place, sensitive to the needs of more vulnerable members of the community, is essential. They should then be supported and enabled to secure the services required to meet their individual and community needs
- informing local people about their rights to challenge poor service quality and gaps in services, for example through the mechanism of petitions.

The National Youth Agency (NYA) has produced a widely used and comprehensive set of tools, including standards, for child participation (Badham and Wade, 2006) offering a rationale for participation that is predicated upon ethical, legal, as well as economic outcomes:

- Children and young people's voice and influence will lead to significant changes for them and the wider community.
- Services will be more effective, better targeted and received. This saves money.
- The health of our democratic community depends on the active involvement of children and young people.
- Local and national policies encourage and require it and our performance will be evaluated on how well we do this.
- The involvement of children and young people is a key to gaining funding and sustaining developments.
- And it is children and young people's right to be involved in the decisions that affect them (Article 12 of the UN Convention on the Rights of the Child).

Children Now magazine in association with Participation Works and the Children and Young Peoples Participation Partnership (Children Now, 2006) have developed a Participation Charter, which states

- Participation is a right
- Children and young people are the best authorities on their own lives
- Participation depends on respect and honesty
- Participation must be accessible and inclusive
- Participation is a dialogue to influence change
- Participation is built in
- Participation is everyone's responsibility
- Participation benefits everybody

Summary 3

Global framework

1989: United Nations Convention on the Rights of the Child (UNCRC) giving all children aged 17 (up to 18th birthday) or under economic, social, cultural, and civil and political rights. 1991: UK ratified UNCRC. 2002: UNICEF commissioned from the Commonwealth Youth Programme a toolkit on meaningful children's and young people's participation, based on the lessons learned.

Major policy drivers

Every Child Matters five outcomes enshrined in the Children Act 2004

Youth Matters

National Service Framework for children, young people and maternity services (2004) Standard 3.

The Children Act 1989 requirements around consulting children in (or at risk of being in) care and in family law proceedings, in considering the child's wishes and feelings..

Regulations passed by Parliament in 2003 allow children and young people to become 'associate members' of a committee of a school governing body

Section 7 of the Education Act 2005

Section 3 of the Child Care Act 2006

The Disability Discrimination Act

4. Analysis: what can be learned from research and practice

Outcomes

In their report comprising a research survey, practice review and user involvement, Fajerman et al (2004) suggest that organisations have been overly concerned with the process of participation and/or the outcomes for children and young people participating. They found less evidence of organisations addressing what had changed or improved at the service level.

Wright, et al, (2006: p.51) discovered in their review of the literature that there is a greater focus on the 'how' and 'what' of participation and less on the 'why'. They state:

The research, practice and consultation materials seem to suggest that participation is 'inherently a good thing'. However, with little evidence from practice of clear purpose or outcomes – how do we know? There are few messages from research or practice on the potential negative impact of participation or of possible detrimental outcomes for children and young people who participate.

In a study that examined genuinely participatory practice with children and young people in case studies of 29 organisations, Kirby, et al, (2003: p.7) identified three types of purpose for participation:

- Practical benefits to services: ensuring adapted or new services best meet the expressed needs of children, as well as offering improved individual client support, improved clients' experience, access and use of services. Involving young people was also seen as a way of improving service accountability.
- Citizenship and social inclusion: Participation was seen as helping to establish inclusive practice, and fulfilling an obligation to ensure children's rights under the UNCRC; to empower children to effect change and to develop the self-belief in their ability to influence outcomes. Participation can offer children and young people opportunities to have increased responsibility within their lives, improve community relationships (between children, and between children and adults) and to enhance community feeling.
- Personal and social development: Participation was also seen as contributing to children and young people's wider personal development, including knowledge, skills and confidence.

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In assessing outcomes, the authors however echoed the findings of Wright, et al (above). Within the case study research, even the organisations that could illustrate outcomes could not always support their perceptions with systematic written evidence and:

Only a few could provide rigorous evaluation or other empirical evidence to demonstrate the relationship between participation and the assumed and promoted benefits

(p.122)

Significantly Kirby et al interpreted the lack of outcome reporting in the case studies as follows:

We also speculate that many agencies, having accepted the principles of participation, have viewed this process as an outcome in itself and have, therefore, concentrated efforts on reflection of the processes of participation rather than what may be achieved through this process.

Where services were able to report outcomes, those benefiting the service itself included practical outcomes such as improved service development and client support, as well as increased access and use of services and greater participatory practice (p. 124).

Additionally, services reported benefits to both themselves and young people, in the area of citizenship and social inclusion, including improvements around children's rights, empowerment, citizenship and political education, responsibility and relationships (p. 134).

The focus of this research was on services and organisations, but the authors also record some of the benefits that accrued for children and young people themselves. Confidence and self-belief were seen to have grown as a result of participation, as were inter personal skills such as working effectively in groups. For young people who could be considered at risk there were also beneficial changes to behaviours, particularly around sexual health, drugs and teenage pregnancy (p.140). A major area of benefit to young people was reported by staff as the development of practical skills, which included (p.141):

- Technical skills – such as: filming, editing, website design, information technology.
- Organisational skills – such as: presentations, facilitation, recruitment and selection, minute-taking.
- Creative skills – such as: acting and writing newsletters.
- Workplace skills and experience – such as: applying oneself in a working environment, adhering to guidelines, attending meetings, working in a large business environment, assertiveness, coping with stress, and time management.
- Presentation and language skills
- Other skills – such as: decision-making, public speaking and media relations.

Day (2008, p.3) asserts that although often seen as an objective in itself, participation and involvement is in fact used to fulfil a range of objectives, including:

- Improving quality and effectiveness.
- Meeting rights and obligations.
- Involving consumers and stakeholders.
- Empowerment.
- Developing skills and competencies.

These are not mutually exclusive and will often be used in combination. Day discriminates between approaches that involve children and young people in their own mental health care and those in which they participate in service development, asserting of the former that:

Little is known about whether the types of tools and methods described above are useful in facilitating children and young people's involvement as few have been developed that take account of their directly expressed preferences or have been tested within CAMHS.

(p.4)

In respect of more strategic participation Day contends that:

...service planning is by and large not a democratic process and those involved are largely present by dint of their responsibilities and authority. The same can be said for the involvement of users. It is therefore important to establish users' participatory responsibilities and authority from the outset.

(p.5)

Differentials of power and authority need to be addressed if children and young people are to be able to participate on an equal footing to other stakeholders and attention needs to be paid to approaches and techniques for their involvement. A helpful overview of approaches, with the strengths and weaknesses of each, has been provided by Street and Herts (2005).

The national charity YoungMinds has hosted a young people's participation group with a virtual forum, *Healthy Heads* and a national group called *Very Important Kids* (VIK). The young (ex) service users who comprise VIK (2007) state that participation is important for children and young people as it can result in:

- feeling empowered to be involved in decision making
- increased self esteem and self efficacy
- improved services.... "sometimes children and young people do know best what they need- adults don't always get it right, and should be prepared to learn from us too"
- greater insight into their own thoughts and feelings
- confidence
- development of their own thoughts and feelings
- greater independence
- an understanding of the value of their own experiences and ability to use those experiences in a positive way

What children and young people want

As part of the seminal research resulting in the publication of *Bright Futures* (Mental Health Foundation, 1999), Laws (1998) aimed to develop effective ways of consulting with young people who were experiencing mental health problems and ensure their voices were heard and influenced the provision of services. Laws asked what we have learned about young people's views on mental health services. This question is particularly germane to the explicit aim to "turn what young people say into what services do". The conclusion was that young people need to be listened to and feel involved in their care. They want to be treated as individuals and not feel "like a number." Young people want a timely response from services and find waiting times too long. They value counselling services and want to know about a range of treatment options, not just medication. Young service users require information – about the local services and the people who work in them, as well as about the range of mental health problems and their treatments.

Amongst the key findings of Kurtz et al's (2005) report there was very limited understanding of mental health and mental health services and even when young people had recognised the need for help and support they and their families had no idea how to gain access to services. Many of those interviewed indicated that young people tended to approach services only when they had reached a crisis point. For young people from Black and minority ethnic groups it was important that staff were culturally sensitive and competent, though this was not always their experience.

The suggestions made by young people for improving services were primarily for more information, but also ideas for improving the style of delivery of specialist services, including access and staffing.

These are elaborated in the boxes below. Subsequently the findings have been echoed in the interim report of the national review of CAMHS (Davidson and Jezzard, 2008).

Box 3. Young people's suggestions for improving information about services (Kurtz et al 2005)

Types of information

- What mental health is and how mental health problems may affect you.
- What CAMHS/mental health services do - who works in them, what treatment they offer and how to access them.
-

Information on:

- drug and alcohol problems
- how you can help yourself including strategies for managing anxiety and depression, exercise and relaxation techniques
- how past experiences can affect how you feel in the present and how stress can affect you
- how different services - for example, health and social services, work together and how and what information is shared between them
- about services in your local area including voluntary sector projects and drop-in resources.
-

Routes for information sharing

Sharing information by workshops or drop-in sessions, through the following routes was seen to be non-stigmatising:

- schools
- colleges
- youth clubs
- sports clubs
- radio and television
- churches and local faith groups
- other venues used by young people for socialising
- email, internet and text messaging.
-

Box 4. Young people's suggestions for the style of specialist mental health service delivery (Kurtz et al 2005)

The prominent theme was that services need to be more flexible and welcoming to young people and it was suggested that access to CAMHS would be improved by:

- staff working in different venues, including in young people's own homes
- being open at different times, notably in the early evening and at weekends
- the use of community settings such as school and college facilities
- adaptability about the frequency and length of appointments, including the provision of appointments or drop-in times for crises
- availability of interpreters and translated materials
- peer support and involvement
- the provision of information on self-help strategies and techniques
- staff groups in CAMHS being representative of the local community they are serving.
-

Other findings are in keeping with the suggestions given above (Curtis et al, 2004, Swales, 2005), demonstrating that young people emphasise the importance of communication and relationships with staff on their experience of health services.

Curtis et al (2004) conducted a study with young people aged between 4 and 19 years, from community and clinical settings. This included hard-to-reach children, including those leaving care, those in touch with the criminal justice system, asylum seekers, and those with learning disabilities. Broadly The authors state that, whilst what children had to say was revealing, they were aware that the observations did not provide particularly dramatic insights to those working in children's services in the NHS and this was borne out by clinicians and managers, to whom the findings were fed back. This poses a significant question,

This, in a sense, is a key finding. If practitioners and managers have known for so long that the issues raised here are problems, (and we have no reason to doubt this), why are we so poor at acting on this knowledge?

Curtis et al (p154)

The answers suggested are that children tend not to have sufficient power for their voice to be heard and consulting children and responding to what they say has not always been part of recent NHS reforms. Disruptions in NHS structures, mergers and changes, often promoted as improving efficiency and reducing costs, result in considerable disruption and there are few incentives for individual practitioners to improve their own service, and act on feedback from children.

VIK (2007) state that participation must lead to change, so that children and young people can see that what they suggested was not just "noted", but led to discernible change. This echoes findings by Fajerman et al (2004), who report that adequate feedback includes information about how views have (or have not) been taken forward and Street and Herts (2005), finding that being consulted repeatedly when nothing actually changes leads to "consultation fatigue".

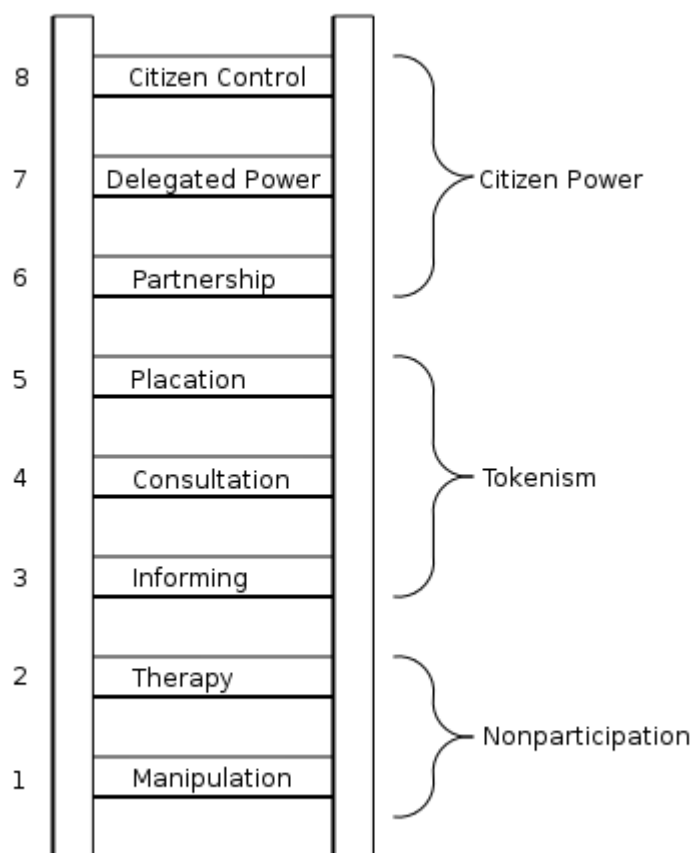
According to VIK children and young people need to be involved not simply in every day decision-making, but at a strategic level, which includes having systems in place for direct contact with commissioners. This could include the establishment of community meetings run by children and young people.

Models of participation

The notion of levels of participation has been current at least since 1969, around the time of mass student demonstrations across the world, particularly in France and the USA, when Sherry R Arnstein originally published *A Ladder of Citizen Participation*. The original work that proposes a typology progressing in steps from "non-participation" through to full citizen control, was made freely available by the author in 2004 (see references section for web link).

The "ladder of citizen participation" is well known and has been referenced, modified and implemented, specifically within the voluntary sector, for many years. Whilst the ladder has been freely adapted (notably in the UK by the Social Care Institute for Excellence and the Joseph Rowntree Foundation), it has rarely been supplanted and continues to hold an intuitive appeal.

Figure 1. Ladder of citizen participation



The continuing appeal of Arnstein's typology is twofold. First it represents steps towards full participation in a readily recognisable and familiar graphic form. Second and more importantly, the ladder is predicated on principles of equity and power sharing. The following is taken from Arnstein's opening comments:

...citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future. It is the strategy by which the have-nots join in determining how information is shared, goals and policies are set, tax resources are allocated, programs are operated, and benefits like contracts and patronage are parceled out. In short, it is the means by which they can induce significant social reform which enables them to share in the benefits of the affluent society.

Arnstein, 1969

The "have-nots" exist in all societies and in the health and social care systems of developed countries may also be taken to include those service users who, by virtue of their health and/or social care need are at risk of disadvantage and inequity. Such groups would include particularly, children, elderly people, those with a disability and those with severe and enduring mental health problems. This extrapolation is made by Arnstein early in the original article:

The underlying issues are essentially the same - "nobodies" in several arenas are trying to become "somebodies" with enough power to make the target institutions responsive to their views, aspirations, and needs.

Arnstein, 1969

The strength of the ladder lies in its iconic familiarity and simplicity, yet these are also limitations. As Arnstein states, the “have-nots” who are seeking greater involvement are not a homogeneous group and progress up the ladder is not predictable. Moreover, whilst the ladder gives eight rungs to represent upward stages in participation, the reality could be fewer or more steps, depending on circumstances. Wilcox (2004), writing about his own adaptation of the ladder for the Joseph Rowntree Foundation states:

When I amended the ladder I suggested that it was not really a matter of the higher up the ladder the better, but rather horses for courses. Sometimes consultation on fixed options would be appropriate, sometimes a partnership among stakeholders, or support for key interests. Unfortunately things seldom work out that cleanly, and I think that Sherry may have been right to include terms like manipulation and therapy in her model.

The Wilcox adaptation is summarised below:

Figure 2. Adapted participation model (Wilcox 1994 for Joseph Rowntree Foundation)

<p>Information The least you can do is tell people what is planned.</p>
<p>Consultation You offer a number of options and listen to the feedback you get.</p>
<p>Deciding together You encourage others to provide some additional ideas and options, and join in deciding the best way forward.</p>
<p>Acting together Not only do different interests decide together what is best, but they form a partnership to carry it out.</p>
<p>Supporting independent community initiatives You help others do what they want - perhaps within a framework of grants, advice and support provided by the resource holder.</p>

The typology has been quite widely adapted for use in children’s participation. Hart’s (1997) book on children’s participation for UNICEF presents a refinement of Arnstein’s ladder that makes it more applicable to children (see Figure 3). In turn Hart’s work has been further adapted as a spiral of participation, representing the cyclical and developmental nature of participation, rather than the linear model implied by the ladder.

One of the better known and used developments of Hart’s ladder has been proposed by Shier (2002), consisting of five levels of participation (see Figure 4). It is recognised that individuals and organisations have different degrees of commitment to the process of empowerment and this is reflected by identifying three stages of commitment at each level - openings, opportunities and obligations.

Figure 3. Ladder of Children’s participation (Hart, 1992)

Step	Level of participation
Youth-initiated, shared decisions with adults 8	Children/young people have the ideas, set up the project, and invite adults to join with them in making decisions.
Youth-initiated and directed 7	Children/young people have the initial idea and decide how the project is carried out. Adults are available but do not take charge.
Adult-initiated, shared decisions with youth 6	Adults have the initial idea but children/young people are involved in every step of the planning and implementation. Their views are considered and they are involved in taking the decisions.
Consulted and informed 5	The project is designed and run by adults but children/young people are consulted. They have a full understanding of the process and their opinions are taken seriously.
Assigned but informed 4	Adults decide on the project and children/young people volunteer for set roles within it. Adults inform them adequately and respect their views.
Tokenism 3	Children/young people are asked to say what they think about an issue but have little or no choice about the way they express those views or the scope of the ideas they can express.
Decoration 2	Children/young people take part in an event, e.g. by singing, dancing or wearing T-shirts with logos on, but they do not really understand the issue or goal.
Manipulation 1	Adults lead children/young people in accordance with a scheme known only to the adults. The children/young people do not understand what is happening. They are not free to explore or act on their own thinking.

Whilst the journey from disenfranchised have-nots to empowered and involved citizens is uniquely complex to each individual or group, the ability to judge the efforts of health and social care organisations in moving towards user participation needs to be simple, transparent and understandable. Typologies lend themselves to such assessments and may be used as a starting point in determining for any organisation how much progress has been made and what is still to be attained. As Day (2008, pp2-3) states:

These models help to break down the inherent complexities of participation and can be used to plan and critically appraise specific initiatives. They have a more limited role in explaining the interplay between the needs of children and young people and those of other users such as their parents and carers or helping to understand when children may want to delegate or entrust involvement to others on their behalf.

Figure 4. Pathways to Participation (Shier, 2002)

LEVELS OF OPENINGS	OPPORTUNITIES	OBLIGATIONS	PARTICIPATION
5. Children share power and responsibility for decision-making.	Are you ready to share some of your adult power with children?	Is there a procedure that enables children and adults to share power and responsibility for decisions?	Is it a policy requirement that children and adults share power and responsibility for decisions?
4. Children are involved in decision-making processes	Are you ready to let children join in your decision-making processes?	Does your decision making process enable you to take children's views into account?	Is it a policy requirement that children must be involved in decision-making processes?
3. Children's views are taken into account.	Are you ready to take children's views into account?	Does your decision making process enable you to take children's views into account?	Is it a policy requirement that children's views must be given due weight in decision-making?
2. Children are supported in expressing their views.	Are you ready to support children in expressing their views?	Do you have a range of ideas and activities to help children express their views?	Is it a policy requirement that children must be supported in expressing their views?
1. Children are listened to.	Are you ready to listen to children?	Do you work in a way that enables you to listen to children?	Is it a policy requirement that children must be listened to?

The linearity and hierarchy implicit in models that encompass levels or stages has been challenged and alternatives have been proposed. A different approach is to create a conceptual framework based on the ways that organisational structures and cultures either promote or inhibit participation (Kirby, et al, 2003). The first of the two frameworks describes organisations' orientations as:

- Consultation-focused, in which children's participation is viewed as informing service development.
- Participation-focused, in which children are involved in decision making, though often in time-limited and context specific ways.
- Child/youth-focused organisations, in which children's participation is pivotal and children participate in all decisions affecting their lives.

(Kirby et al, 2006, p.6)

Importantly the three approaches to participation are not intended to be viewed as steps or stages, but each may be used appropriately according to local circumstances and the intended purpose.

The second framework proposes four stages in the process of changing organisations' cultures in order to embed participation within them:

- Unfreezing existing attitudes, procedures and styles of working.
- Catalysing change and developing a vision of children's participation.
- Internalising change through communicating and developing a shared vision and understanding of participation.
- Institutionalising change by mainstreaming practice across different organisations.

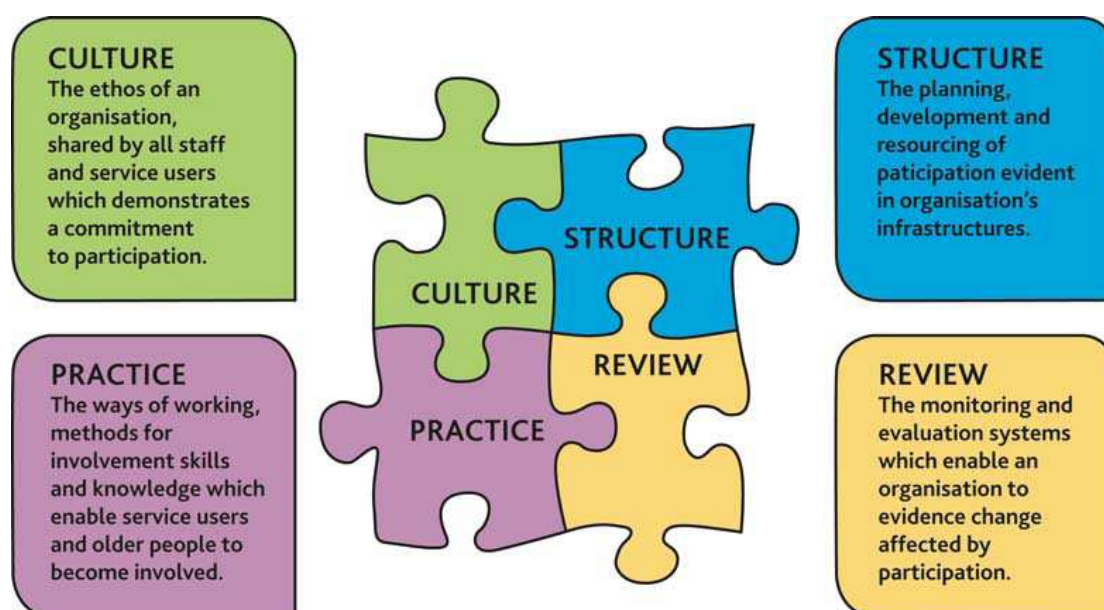
Wright et al (2006, p.13), in endorsing the whole systems approach adopted by Kirby et al, offer four interlocking areas that are presented graphically as jigsaw pieces:

- Culture: the ethos of an organisation, shared by all staff and service users, which demonstrates a commitment to participation
- Structure: the planning, development and resourcing of participation evident in an organisation's infrastructures
- Practice: the ways of working, methods for involvement, skills and knowledge which enable children and young people to become involved
- Review: the monitoring and evaluation systems which enable an organisation to evidence change affected by children and young people's participation

The authors stress their structure is complementary, rather than an alternative to previous models of participation, bringing together the overarching themes from the literature into one framework. They state,

The jigsaw demonstrates how each of the four elements can be considered separately or added to the puzzle in different sequences to produce the same outcome – the change or improvement of organisations.

Figure 5. Whole systems approach to participation (SCIE)



Summary 4

Outcomes of children and young people's participation

These may be outcomes deriving from undergoing the process, benefits and risks to the young participants themselves, and/or consequences involving change for organisations.

What children and young people say they want

Meaningful participation, based on equity and mutual valuing and resulting in visible change.

Models and typologies

The original model of participation was Arnstein's ladder, which has been modified and adapted many times. It portrays the steps involved in moving from tokenism and disempowerment to full participation. Hart adapted the ladder specifically for children's participation. Alternatives to a stepped model focus on organisational culture and structure and a whole systems approach.

5. Praxis: informed action

Who can participate

Street and Herts (2005) suggest that in addition to service users it is important to involve non-users of services or those who fail to attend. They state that this is an important group that can help services understand ways to improve access and acceptability and thus identify ways to improve engagement.

If services are to participate with children and young people across all communities, special attention needs to be paid to those from excluded groups and those whose first language is not English. A key recommendation of a report that looks specifically at the needs of children and young people from Black and minority ethnic groups advises:

The lack of awareness and understanding and the poor perception of services that promote mental health, amongst many young people from Black and minority ethnic groups and their parents, must be addressed. New sources of information about CAMHS are needed, to be disseminated more widely, including through 'non-traditional' routes that young people may be more interested in using such as the internet, media/radio, social and local faith groups. It will be important to consider that this information is made available in a variety of languages, addresses the information needs of parents and is accompanied by education and training at the primary care level to improve the early recognition of mental health difficulties and the appropriate referral on to CAMHS.

(Kurtz et al, 2005, p.)

Many studies and research papers focus on the findings of consultation and participation with older children and adolescents. There are special techniques and unique considerations for working with younger children (Clark, et al, 2003, McAuliffe, 2003, Penny Lancaster and Broadbent, 2005, Willow et al, 2004).

Willow et al (2004, p.29) found little evidence that younger children were being allowed, encouraged or supported to influence decision making, whether at an individual, local or national level. The authors ask why participation seems to focus on adolescents and suggest the answers lie in legal changes, self-advocacy and the scale of the challenge, all inter-woven with adult perceptions and expectations. The legal framework for children is broadly contained within the Children Act 2004 and the Education Act 2002, both of which have requirements for consultation and participation, but issues around children's competence and the place for parents and carers seems to deter services from involving the younger age group.ⁱⁱⁱ Self advocacy has become a feature of the looked after system, but again, despite over-arching policy and guidance, the voice of the younger child has gone unheard (Willow et al, 2004, p.51). Willow et al also argue that because of the ways in which decisions are made through public bodies and formal meetings, barriers are created for most people outside of those organisations that are impenetrable for very young people.

Young children experience a lack of respect and are easily patronised (Willow et al, 2004) and even in the childcare audits carried out by Early Years and Childcare Partnerships during 2001-2002 only a minority had focused on the views of children under five years old (Clark et al, 2003).

Willow et al (2005, p.32) state:

The way they communicate and what they communicate is more often seen as cute, funny or obscure rather than as intelligent, insightful or challenging.

Issues to address

Children and young people's participation within any arena will bring its own challenges and these need to be acknowledged and managed. Wolpert et al (2001, p.3) offer a list of such considerations for participation in a mental health setting. It can be seen however that excepting the last point, the issues could apply to any group of service users:

- Cognitive abilities, considered generally in developmental terms or as specific areas of impairment in certain children.
- Aspects of disability.
- Language; differences between children and adults, differences of first language.
- Cultural and religious practices and beliefs.
- Motivation, including disaffection on the part of the young person in some cases.
- Emotional maturity.
- The effect of the child or young person's presenting mental health difficulties on attention and decision-making (for example, the influence of depression or delusional thinking on a client's outlook).

Timing

In CAMHS specifically there may be concerns about the timing of participation for young service users. During treatment for a mental health difficulty children and young people are by definition unwell and it may not be the best time for them to give meaningful thought to service developments and improvements. Street and Herts (2005, p.6) state:

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.

Even after treatment, being involved with a service may have difficult associations for children and young people and this also needs to be anticipated and managed.

Overcoming barriers

There is an obvious power differential between professionals and non-professionals within service settings and this can only be exacerbated by situations involving professional adults and non-professional children and young people. Young people may feel intimidated by professional language and formal meetings may seem tedious and difficult to understand, especially when adults appear to be making the decisions. YoungMinds has found that young people can "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" (Street and Herts, 2005).

Parents and carers may also feel intimidated and often have the additional concerns of childcare, transport problems and the need to take time off work.

Staff undertaking participation work also face barriers. The culture of the organisation might not feel supportive (Kirby, et al, 2003, Fajerman et al (2004) Wright et al (2006) and this will affect how well the participation programme is resourced, both in direct funding as well as in releasing staff time. Many staff will be unaccustomed to involving children and young people and may have concerns about young service users having unrealistic expectations.

Many adults are resistant to change and just as children may acquire “consultation fatigue” (see above), so public sector workers could be argued to have “change fatigue”. Participation may be seen as just one more onerous task, to add to all the others.

The danger of course is that weariness with change and concerns about barriers and risk can lead to inertia. Jerry Robinson, renowned business consultant, in an interview on his involvement with the NHS, made the following comments in relation to attitude change:^{iv}

And it was very clear that to get any change at all, to get people to think that you could actually do something now rather than waiting six months or maybe a year, sometimes two years to actually do something - you talk about it now but you don't actually do it now – just getting that idea into people's head that you need to get out there, look at what the problem is, solve it now and move on.

Summary 5.

Issues

Appropriate responses are needed in order to manage the challenges posed by age, level of (dis)ability, service usage/history, timing. Organisations need to be culturally competent in the fullest sense.

Barriers and how can they be overcome

Barriers include attitudes and constraints within organisations and the individual within them, issues around consent and the role of parents, concerns around the young person's mental health difficulties. Professionals may feel beleaguered by increasing levels of change.

All participants, adults and children and young people, need organisational support.

Children and young people are citizens now.
As citizens, they have the right to participate in decisions that affect them.
This places a responsibility on agencies to open up their processes and
engage children and young people in **dialogue**.
Dialogue is *different* from consultation.

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6. Conclusions and action summary

Real participation

Clear and consistent themes emerge from this review of the literature and these are summarised below.

There is much that we already know about what children and young people want from services and, more broadly, from participation. From services children and young people want their voice to be heard and to be taken seriously. They want plenty of information in a variety of formats, so they are better informed about the nature of their difficulties and the range of options available to them for support and care. In participation children and young people want to know that they are acting as citizens, on an equal footing with adults, within a process that is genuine, not tokenistic.

All children and young people can participate, they just need to be invited. Genuine participation will seek out the groups that tend to be excluded or marginalised and will adopt special methods and techniques for children who are very young, from a minority ethnic group, with insecure status such as being homeless or asylum seeking, or those who are simply more challenging to identify and engage with.

Real participation has demonstrable outcomes, both for the individuals involved – whether young people or adults, as well as for the organisation. Monitoring and review have to be built into participation from its inception. If participation does not make a tangible difference it begs the question of why it took place.

For participation to be effective in improving supports and services, careful preparation is required. Organisations need a culture and structure that will enable participation, not constrain it and this requires support from senior managers, including commissioners. Individual staff may have concerns about participating with young people as equals and these need to be addressed and resolved. Planning for participation should include education, training and support, especially for young people who are less familiar with organisational processes and procedures.

Decision-making within a participative climate will probably look and feel very different from what professionals are used to. Formal committees and board meetings may need to be replaced or augmented by more creative ways of exploring ideas and reaching agreement.

Doing it

Drawing upon the findings of this review the following is offered as a simple model for getting started, building upon the *What and Why* offered by the Commonwealth Secretariat (2005c). Practical tools and guides that will help in getting started and in sustaining effective participation can be found in the *Interactive Annotated Bibliography*, comprising International institute for child rights and development, (2006), Children's Rights Alliance for England (2005), Commonwealth Youth Programme, (2005b), National Evaluation of the Children's Fund, (2005), Street & Herts (2005), Kurtz et al, (2005), Penny Lancaster & Broadbent, (2005), Kirby et al, (2003) and websites *Investing in Children Development Agency, Participation Works*.

Box 5. Getting started

What	Why
Disseminate this <i>Review for Informed Practice</i> and <i>Interactive Annotated Bibliography</i> to all stakeholders, including young people.	Ensures everyone is clear about what participation means, why it needs to happen and how it will be carried out and evaluated.
Start talking – hold an event or a series of events, create a blog or other e-forum, piggy-back on to existing groups and forums. Use techniques and methods suggested in the practical guides.^v	Starts as you mean to go on by talking and listening, sharing and recording ideas. Begins to shape the culture of participation.
Begin to formulate your vision together. Think together about the intended outcomes. Record the agreed decisions.	Promotes shared goals. Starts to identify benefits, costs and risks.
Secure agreement and support from senior members of the organisation(s), including commissioners.	Begins to address resourcing requirements (time, funding and premises). Starts the process of building sustainable structures.
Create a strategy or plan, containing milestones and outcomes to be monitored and reviewed together.	Moves you from good ideas to something more tangible. Helps to keep senior managers informed and in support.
Consider/amend and adopt the <i>Quality Standards for children and young people’s Participation in CAMHS</i> (see below).	Creates a framework for continuing to build structures and a culture that will sustain participation throughout the organisation.

Quality standards for children and young people’s participation in CAMHS.

The *Interactive Annotated Bibliography* locates a range of published standards for assuring quality in children and young people’s participation. Most of these have derived from the National Youth Association’s (Badham and Wade, 2006) *Hear by Right* and/or Save the Children’s (2005) *Practice standards in child participation*.

Hear by Right is a framework for organisations across the statutory and voluntary sectors to assess and improve practice and policy on the active involvement of children and young people. It is based on the “Seven S model of organisational change”: Shared values; Strategy; Structures; Systems; Staff; Skills and knowledge and Style of leadership.

The framework has been implemented and evaluated across time and in a range of settings. Since *Hear by Right* relies on self-assessment, it integrates well with the CAMHS Self Assessment Matrix, an on-line tool^{vi} used by CAMHS partnerships to monitor their progress towards achieving the standards set out in the national service Framework for children, young people and maternity services (Department of Health, 2004).

An adaptation for use specifically in CAMHS has been produced for the Care Services Improvement Partnership (CSIP) for the North West^{vii} and further modified as part of this project. The *Quality standards for children and young people’s participation in CAMHS* will undergo additional modification following the involvement of children and young people, when they will be added to the CAMHS self assessment matrix.

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Literature search

There is rarely an abundance of peer reviewed literature for topics around CAMHS and it is helpful to work beyond the usual academic search criteria. The databases Medline and PsycINFO were searched initially for peer reviewed items. From these search results additional references and citations were followed up. Google was also used as the starting point for the search and to locate documents that are in the public domain, but unlikely to show up in a search of academic databases.

The search term combinations are provided below. At the search stage exclusions were not used, although primacy was given to literature from the UK.

Search term combinations

child	participation	standards
children	involvement	policy
young person	consultation	model
young people	research	service
adolescent	findings	mental health
young adult	outcomes	emotional well being
CAMHS	evaluation	strategy
youth		procedure

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Note: the original search took place in the summer of 2007, but was updated in March 2008 prior to publication.

ⁱ The CYPU was disbanded in 2003 and absorbed into the Children, Young People and Families Directorate within the (then) Department for Education and Skills

ⁱⁱ Now encompassed within Joint Area Reviews

ⁱⁱⁱ A judgment in the High Court in 1983 laid down criteria for establishing whether a child, irrespective of age, had the capacity to provide valid consent to treatment in specified circumstances. These were approved in the House of Lords in 1985 and became widely known as the "Gillick test," after the mother who had challenged health service guidance that would have allowed her daughters aged under 16 to receive confidential contraceptive advice.

^{iv} "Can Gerry Robinson fix the NHS?" http://www.open2.net/nhs/gerry_interview_general.html

^v The *Interactive Annotated Bibliography* contains a number of references for practical support and guidance in implementing children and young people's participation. Many of these guides have been drawn up by or with children and young people themselves.

^{vi} http://www.childhealthmapping.org.uk/self_assessment/

^{vii} Acknowledgement to Lisa Nolan, CAMHS co-ordinator for Liverpool PCT, seconded to CSIP in 2007 to develop CAMHS participation work