

**Table 5. Barriers to participation for groups of young people**

- ☐ Young people who have had a difficult life experience may be less likely to have the confidence and self-esteem to participate.
- ☐ Young people are also likely to be put off participation if they have had previous problems communicating in groups.
- ☐ If young people's views have not been taken into account in the past, they are less likely to be motivated to participate in the present.
- ☐ If life experiences have included mistreatment by adults, they are less likely to trust the current intentions of adults trying to engage their participation.
- ☐ Negative assumptions and stereotypes that can be applied to young people generally may be even stronger for some groups of young people.

**Adapted from McNeish (1999)**

### **3.2.9 Disabled CYP**

Article 23 of the UNCRC specifically refers to the importance of recognising the right of disabled CYP to participate. Dickens *et al* (2004) state that disabled children are more vulnerable to abuse than non-disabled children and are more likely to receive medical treatment and to be involved in various assessment procedures about their care. For these reasons, it is essential that disabled CYP are routinely involved in both micro and macro aspects of care, in addition to service delivery.

Franklin & Slopers research (2004) into the participation of disabled CYP in Social Service departments found that 'their participation is still patchy and involvement at a higher strategic level is rare'. Findings included 60% of the 71 local authorities involved, reporting that they involved disabled CYP in both service development and in tailoring individual care packages. Respondents also reported that they felt they had received insufficient training about communicating with young disabled people. Results demonstrate that disabled children are being involved in a range of decision-making areas, however, participation is not yet embedded or sustained across all health and social services departments, and the involvement of disabled children at a higher strategic level is still rare. The participation of disabled children therefore needs further development including more evidence on which factors can support and promote disabled children's effective participation. Franklin and Sloper (2004) determine from the evidence gathered through Quality Protects and other similar projects elsewhere, that while in general CYP are increasingly involved in decision-making, growth has been slower in respect of involving disabled children directly (Council for Disabled Children, 2000; Sinclair & Franklin, 2000; Robbins, 2001)



In addition, a review of the literature undertaken by Cavet & Sloper, (2004 a,b) also concluded that as evidence of good practice is sparse, the participation of disabled children needs further development. The review by Cavet & Sloper (2004b) revealed that some disabled children had not been afforded their full participation rights under the Children Act 1989, and/or the UNCRC, due to a lack of availability of communication aids to those CYP who rely on them (Morris, 1998a, Stone, 2001; Rabiee *et al*, 2001). Furthermore, Cavet and Sloper's (2004 a,b) review on participation of disabled children highlighted that in order to promote participation, staff training, education and skills development was essential. This included attitudinal changes, training about communication, disability equality and children's rights. The conclusion echoes findings from Kilgour's (2002) survey of participation workers, which revealed the needs amongst these workers for specialist advice, support, training and networking opportunities. This survey sought information on whether initiatives provided any training to support staff in their role.

Despite emerging literature presenting general lessons for those wishing to involve disabled CYP, by highlighting that dedicated resources, attitudes of adults and feedback are important and should be used (Treseder, 1997; Cohen & Emanuel, 1998; McNeish, 1999; Kirby *et al*, 2003; *Listen Up*, 2005; *Ask Us*, 2005). There are still substantial gaps in knowledge about both the process and outcomes of disabled CYP's participation (Franklin & Sloper, 2004). In particular, little is known about CYP's experiences and their views as to what might constitute good practice in the process of participation or indeed what should be the outcomes of their involvement.

Furthermore, Franklin and Sloper (2004), highlight the lack of evidence that exists about the outcomes of disabled CYP's participation in terms of its likely impact on service planning and/or individual packages of care. Interestingly, although not necessarily relating to disabled children, others (Kirby *et al*, 2003; O'Malley, 2004 and Wright *et al*, 2005) advocate the same principle across the board of all CYP's participation initiatives.

Lightfoot & Sloper (2004) sought further information on the methods of involving disabled CYP. Service delivery respondents were asked which methods are used to facilitate children's involvement (e.g. written, verbal, visual, computer/IT). Although asked to specify, there was a large amount of missing data, in some cases almost half of respondents failed to provide any further details. Interpretation of these results should therefore be treated with care. However, of the 65 areas/teams, 34 (52%) involving disabled CYP within decisions about their own care were using a **written method**, in most cases a questionnaire or consultation form. Within the area of service development, 38 of the 70 initiatives (54%) were using written methods predominantly questionnaires, although some employed newsletters, graffiti walls, or distributed from meetings usually at youth forums. Fifty-five of the 65 area/teams (84%) involving disabled CYP in their own care were using **visual methods** to facilitate involvement, in most cases using Symbols, Makaton, PECs and signing or toolkits such as '*I'll go first*'. Forty-six of the 70 service development initiatives were also adopting visual methods. Art and drawing featured highly across both decision-making areas, and creative methods such as photographic diaries and videos were being employed. Observation work was also mentioned in a few cases, possibly indicating some move towards including children with severe disabilities and/or communication details.



### **3.2.10 Long Term/Chronic Illness**

A study by Dovey-Pearce *et al* (2005) which investigated Young Adults' (16-25 years) suggestions for providing developmentally appropriate diabetes services identified an apparent lack of user involvement in service development. This qualitative, user involvement study aimed to describe and understand the considered opinions of 19 young adults with diabetes who were receiving secondary care services about the provision of diabetes services for young people. Ory & Kronenfeld (1980) and Miller (1999) also interviewed CYP with Diabetes Mellitus about living with this long-term illness.

Other innovative work includes Kendall *et al* (2003) who explored the views of young people with congenital cardiac disease on designing the services for their treatment and Callery *et al* (2003) who has undertaken extensive work with children with asthma in a participatory framework using one to one interviews. There is also much written about using draw and write methods when eliciting CYP's views (Pridmore & Bendelow, 1995; Action for Sick Children, 1998; Coates, 2004). We found that this technique had been particularly (but not exclusively) used with CYP with long term illness such as in the fields of oncology (Bradding & Horstman, 1999; Gibson *et al* 2006). All the findings of these studies have potentially wide-reaching implications across primary and secondary healthcare, and across agencies providing services to CYP, in terms of facilitating a person's transition through adolescence and into young adult life in all aspects of healthcare.

### **3.2.11 Asylum Seekers**

Hek (2005) reflects that whilst the healthcare needs of asylum seeking CYP in the U.K. are very complex and that they have difficulty in accessing services, there is limited work available regarding their involvement. Largely, to date, methods include qualitative interviews, which seek to elicit their view.

### **3.2.12 Summary**

Taken collectively, while these results are informative and present an encouraging picture of some areas of development, the number of actual studies is low. Moreover, most are small and descriptive and thus, it remains unclear as to what extent they can be generalised to local or national concerns. Indeed, almost all participants were of school age and included a disproportionate number of adolescents. Participants were generally healthy (discharged as in-patients) or CYP with a non-life threatening illness (acute and chronic). While some studies did attempt to include hard-to-reach groups, these were in the minority. Those particularly under-represented included CYP from BME communities, asylum-seeking CYP, 'looked after' CYP, those with mental health problems, learning disabilities or life-limiting illnesses.

Lack of diversity was also apparent in the use of research design and methods. Nearly all were cross sectional (i.e. data collected at one point in time) and most employed questionnaires, interviews or focus groups. There was evidence of more creative methods (e.g. the use of art) but these were much less. To some extent, this may reflect the fact that most studies were adult led consultations. Indeed only a minority appeared to involve CYP in an active role (e.g. as project advisors or as supported peer researchers. See Coad & Evans in press, 2007).



**Table 6. Examples of published studies showing the involvement of CYP in health service development (UK only) (Source: Adapted from Coad & Shaw, 2006)**

**Key to abbreviations:** C=children; YP=young people; HTR= hard to reach; GP=general practitioner; HS=health service; HP= health professional; CAMHS=child and adolescent mental health services

SERVICE Reference	Aim	CYP	Setting	Study Design	Key Findings
<i>* unable to get full paper</i>					
<b>HOSPITAL BASED SERVICES</b>					
<b>Inpatient</b>					
Alison et al. (Moules, T) 2004	To explore involvement of children in monitoring quality of care in hospital	108 CYP (9-14yrs)	Primary and Secondary school (Chelmsford)	Cross-sectional Mixed methods Questionnaire following a story about a child's experience in hospital	Privacy, good technical skills, explanations, choice and friendly staff identified as key aspects of hospital care. CYP felt that they were most appropriate person to report the quality of care in hospital (as opposed to parent proxies).
Battrick & Glasper. 2004	To elicit views of CYP (and carers) towards their care after a period in hospital as an inpatient	25 CYP (4-16) who had been inpatients	1 regional child health unit (Hampshire)	Cross-sectional Mixed methods 3 age-appropriate satisfaction surveys with qualitative text and drawing facility	Despite explicit instructions, several parents of younger children elected to act as their proxies. Questionnaires completed by CYP showed that most rated their care highly, but wanted wards that were more age-appropriate and which offered greater privacy.
Carney et al., 2003	To investigate CYP's experience of hospitalisation	213 CYP (4-17yrs) recently discharged from a paediatric hospital ward	Paediatric wards of 2 district hospitals (Scotland)	Cross-sectional Mixed methods Questionnaires (structured, unstructured, verbal and visual)	Less than half mentioned procedures associated with their medical treatment. Key themes related to the physical environment and was important to older CYP. Continuity with home life was important.
Coad N & Coad, J et al, 2005	To explore CYP's views of a new PFI hospital environment	60 CYP (and parents) as interviews. 250 retrospective sample of questionnaires	District General Hospital (1 ward, out-patients, discharged patients)	Cross-sectional Qualitative Interviews and art based Questionnaires	CYP had strong views about choice of colour and preferred environment for new hospital environment. CYP expert group trained as researcher which developed into a 'Youth Council' to inform design team.
Needham J. 1997	Describes the setting up of a teenage group to identify their views regarding the quality of care on a specific child and adolescent ward	Core membership: 6 YP who are regular attendees of child & adolescent ward plus YP who were inpatients at time of meeting	1 NHS Trust (Birmingham)	Ongoing Qualitative Focus group	Has had a positive effect on relationship between CYP and staff. Staff more aware of YP's views. Issues discussed have led to a more environmentally friendly ward (e.g. recycling bin, use of 'green' cleaning products) and healthier 'adult-style' menu.
Norwich Union Healthcare, (undated)	To gain the views of YP (and nurses) on the provision of healthcare in hospital	200 YP (13-18yrs) who have spent at least 1 day in hospital	Inpatient units (UK)	Cross Sectional Quantitative Survey	
Sartain SA, et al. 2000	To explore CYP's perceptions about their illness and experiences of hospitalisation	6 CYP (8-14yrs) with chronic illness	3 NHS Trusts (NE England)	Cross-sectional Qualitative Semi-structured interview using drawing technique	CYP can feel alienated in hospital. Engendering a sense of familiarity and normality was important.



COMMUNITY BASED					
Primary Care					
Curtis K et al. 2004	To identify CYP's experiences of local HSS	149 CYP (4-19yrs) from community and clinical settings. Included HTR CYP (care-leavers, YP in criminal justice system, asylum seekers, YP with learning disabilities)	1 Health Authority. Community groups and 4 hospitals (inpatients & outpatients) (London)	Cross-sectional Qualitative Small group discussions, interviews, questionnaires, website data collections Methods partially informed by CYP themselves	Communication and relationship with staff was important to YP. Issues raised as problematic included planning, age-appropriate environments, access for users of wheelchairs, cleanliness, privacy, information, food, access to translation services, waiting times in A&E. Continuity in care and support during transition were valued.
Rabiee P. 2005	To identify the desires and aspirations of CYP with complex health needs (CHN) and those with limited/no speech.	18 children with CHN or NS (6-18yrs).	1 Local Authority. Interviews with CYP performed in own home, respite centre or school (England)	Cross-sectional Qualitative Interviews using visual techniques	CYP raised many priorities for their lives, but few specific examples related to HSS. They wanted HPs to talk to them directly, in a way that they could understand.
Dixon-Woods M et al. 2002	To investigate the views of CYP (and parents) on primary care services for childhood asthma.	20 CYP (8-16yrs) with asthma	2 general practices (1 urban, 1 rural) and cohort from a previous survey (Leicestershire)	Cross-sectional Qualitative Semi-structured interviews	
Jacobson L et al. 2001	To determine how YP view primary care (and how GPs view YP).	1082 YP (14-18yrs)	62 GP practices (South Wales)	Cross-sectional Mixed methods Questionnaire and focus groups	
Linnell 2002*	To ascertain YP's views of local primary care services and how they could be improved from their perspective.			Questionnaire and focus group	CYP wanted positive attitude from HPs, provision of information, access to services, choice and participation. Wanted welcoming décor, choice of good quality food, fun activities, better transition services, to be taken seriously, someone to stay with them in hospital and minimal waiting.
French RS. 002	Examine YP's attitudes towards, and experiences of, consultations with HPs about contraception.	32 YP (16-21yrs) Included some HTR YP (e.g. young mothers, young offenders)	Sexual health services, secondary schools and community projects (London)	Cross-sectional Qualitative In depth interviews and focus groups.	YP wanted developmentally appropriate care based upon shared decision-making, continuity of care and wider access to information and community services. Wanted individualised assessment of holistic needs and increased preparation for transfer.



Hayter M. 2005	To assess YP's views towards sexual health nursing outreach clinics situated in youth clubs	186 YP (13-18yrs)	Sexual health nursing outreach clinics in youth clubs in economically deprived areas (Doncaster)	Cross-sectional Mixed-methods Questionnaires (n=166) and semi-structured interviews (n=20)		Best-practice included the provision of holistic and individualised care, honest explanations of condition and treatment, providing opportunities for YP to express opinions and make informed decisions, continuity in HPs, opportunities for the YP to be seen without parents.
Nwokolo N. 2002	To identify the sexual health needs of YP in order to create a service suited to these needs	744 YP (11-18yrs)	Schools (n=6) and a pupil exclusion unit (London)	Cross-sectional Questionnaire (developed from focus groups with, and facilitated by, YP)		
<b>Mental health</b>						
Dogra N et al. In press, 2005	To explore YP's (and parents') views on mental health services for CYP	15 Gujarati YP (11-16yrs)	Neighbourhood centre (Leicester)	Cross-sectional Qualitative Semi-structured interviews		Wanted accessible services that are visible in community. Wanted staff to respect them and listen to concerns. Issue of ethnicity not specifically identified.
Law S. 1998.	To examine YP's views on mental health by reviewing results of 5 projects.	110 YP (13-30yrs) using wide range of services including users of CAHMS & some HTR YP ('looked after' disadvantaged, excluded from school)	CAMHS, community, education and youth services (England)	Mixed methods. Focus groups, interviews, art, poetry and drama activities. Use of peer researchers.		YP wanted to be listened to, treated as an individual and placed great importance on relationships with staff. YP wanted to be treated as 'competent consumers of services', given more information, be involved in decision-making and given a choice of treatments, not just medication. Having timely help was seen as crucial and YP also called for on-going support after discharge from hospital.
O'Herlihy A et al. Royal College of Psychiatrists' Research Unit (undated)	To explore views of CYP about their stay in psychiatric in-patient units. Part of a larger study.	58 YP staying in psychiatric inpatient units	18 child and adolescent psychiatric inpatient units (England & Wales)	Cross-sectional Interviews Qualitative		Over half reported they were not provided with written information about their problems. Most had not been offered a choice of treatments and a quarter said that they had not been asked for their consent to treatment.
Roose GA et al. 2003	To examine C's views about an appropriate mental health service for their age-group	16 C (10-11yrs)	Primary schools	Cross-sectional Qualitative Focus groups		Suitability of GP as a direct support was dependent on relationship. Preferred talking face-to-face with counsellor than over the phone. Wanted out of school location and stressed importance of confidentiality and friendly, competent HPs
Street C et al. 2005	To give YP from BME a 'voice' regarding their awareness, experiences of and wishes for mental HS	76YP (most 16-18yrs) with and without experience of CAMHS. Included some looked-after YP and some who were refugees	(England & Wales)	Cross-sectional Qualitative Semi-structured Interviews & focus groups		
Stephens, J. 2002	To examine the mental health needs of homeless YP	16 YP (11-25yrs) with experience of homelessness or insecure accommodation	Barnardo's Services	Cross-sectional Qualitative Group discussions		YP reported significant physical and mental health needs but have problems accessing appropriate HSs.



Respite care						
Home care						
Sartain SA, et al. 2001	To compare C's (& parents') experiences of hospital & home care for acute illness in children.	11 C (5-12yrs) with acute illness	1 large GDH. Interviews undertaken in own home (Wirral)	Cross-sectional Qualitative Semi-structured interviews using drawing technique	Hospital at home service was an acceptable alternative to hospital care where there are essentially nursing needs. Seven of the eleven children stated a clear preference for HAH.	



### 3.3 What are the benefits of CYP participating in decision-making at the collective/macro level?

In anticipation of the UK's quinquennial review to the UN (January 2004), there was a torrent of government initiatives outlining the benefits for health services of involving CYP in matters that concern them. This theme is evident too in recent policy proposals and documents (DH, 2003; DFES, 2003; DH 2004; DfES 2004, ASC, 2006). Similarly, the revised Special Educational Code (SEN) Code of Practice (DFES, 2001a), associated SEN Toolkit (DFES, 2001b) and the Government's strategy for SEN (DFES, 2004) stress the importance of building a 'listening culture' in organisations. In the UK, the Children's Fund, Sure Start and Connexions initiatives all echo this sentiment, requiring services to demonstrate how they have included the views of CYP in their development and delivery (Wright *et al*, 2005; ASC, 2006; NE-CF, 2006). Thus, organisations should ensure that CYP have opportunities to become involved in strategic development and service delivery ([www.scie.org.uk](http://www.scie.org.uk)) as well as ensuring that CYP have opportunities to participate in decision making on an individual level. Drawing evidence together, there would seem to be a range of benefits for organisations in involving CYP in strategic decision-making. Table 7 highlights a range of issues drawn from the literature.

CYP's involvement in making collective choices appears to have personal benefits, including the development of new skills and increased confidence (Cavet & Sloper 2004a, Lightfoot & Sloper 2003). Adults involved in participatory initiatives can also benefit by gaining increased knowledge about children's views and informing personal practice (Cavet & Sloper 2004a, Lightfoot & Sloper 2003). Health professionals involved in participation studies are motivated by the belief that children's involvement in service development will improve the attractiveness of these services and improve take-up (Lightfoot & Sloper, 2003). However, the review found little evidence that CYP's participation in decision-making had currently had a significant impact on health service provision (Cavet & Sloper 2004a; Kirby & Bryson 2002, Coad & Shaw, 2006). Where improvement does exist, it tends to be at only a local level and some have noted that in some cases CYP have a 'novelty' value but little impact is witnessed.

**Table 7. Positive impacts on organisations who undertake CYP's involvement**

- ☐ Service users can offer different perspectives (Steel, 2004).
- ☐ Ensures that money and resources are not wasted (Steel, 2004).
- ☐ It may help with the recruitment of peers for the research, which in turn may help in contacting groups that are difficult to access, e.g. those from BME communities.
- ☐ Disseminate of results and help ensure changes are implemented.
- ☐ Break down discrimination between groups of CYP, particularly if they may not have come into contact before such as able-bodied and disabled young people, or those from different black minority ethnic groups and asylum-seekers (O'Malley, 2004).
- ☐ Can enhance community relations by improving dialogue between CYP, and adults including parents, other residents and professionals (O'Malley, 2004).
- ☐ Services can become more responsive to the needs of CYP and can begin to challenge presumptions about the needs of CYP (Wright *et al*, 2005).
- ☐ Services can become more accessible to CYP (Wright *et al*, 2005).
- ☐ Services can become more efficient as they are providing a more effective service to CYP (Wright *et al*, 2005).



When involving CYP several authors have highlighted the benefits in terms of the dissemination of research, including those involved in the project and the readers (Morrow, 2001a; 2001b; Coad *et al*, 2006 in press). Involving local and national professionals throughout the project may help the commitment to the agenda. This is particularly relevant to those who will have to act upon the findings and recommendations of the project, so in turn fuelling the change agenda (Stafford *et al*, 2003).

### **3.4 What are the barriers to CYP participating in decision-making at the collective/macro level?**

What many of the key authors report is that despite such potential benefits there is little evidence of CYP's involvement being fully participative (See *Figure 1*). A significant barrier relates to differential views of CYP. The traditional view of 'children' has regarded them as "developing beings" whose competence to exert their civil rights is reached only in adulthood. More recently, however, CYP are viewed as being competent reporters of their experience and wishes and as possessing information about their lives that is both valid and reliable. As highlighted elsewhere, even young children are capable of making competent and appropriate health decisions (Kalnins *et al*, 1992; Alderson & Montgomery, 1996). This said, defining competence can be contentious when children are very young, have mental health problems, cognitive impairment or learning disabilities (Alderson & Morrow 2005; Tates & Meeuwesen 2001; Moore *et al*. 1998). Regardless of the legal debates, lack of competence does not remove the right to express a view. People cannot be considered unable to make a decision until all practical steps to help them to do so have been exhausted. Lack of competence cannot be attributed solely in reference to a person's age, appearance, or condition of their behaviour (Mental Capacity Act, 2005).

There is unlikely to be a blanket answer in terms of CYP's ages concerning when competence to make a choice can be assumed and indeed this debate is beyond the scoping of this review. As Masson (2001) notes, competence is directly related to the decisions to be taken and so will vary from one situation to the next. It is very clear, that offering CYP participation in decisions regarding their own healthcare will be very dependent upon the attitudes of health professionals and their skills to manage a three-way relationship between themselves, the child and their parents. Unfortunately, as previously mentioned, staff training in communication with CYP is less than optimal (Hart & Chesson, 1998), especially outside the paediatric setting where significant numbers of CYP may find themselves cared for by individuals with no paediatric training whatsoever (Hart & Chesson, 1998).

A further barrier is the lack of evaluative research regarding the interactions between staff/child/parent (Tates & Meeuwesen 2001), particularly from the perspectives of CYP (Crossley *et al*. 2005), which makes it very difficult to discern the most effective methods. As shown in Table 8, compounding factors that have influenced CYP's participation have been noted by several authors. Unfortunately, while many NHS Trusts have written strategies for patient and public involvement, Lightfoot and Sloper (2003) suggest that their systems to recognise this are less well developed and generally fail to identify children as service users. This is of great concern, as CYP have special requirements for their participation, which are unlikely to be catered for within adult-centred strategies (Lightfoot & Sloper 2003).



**Table 8. Factors that influence and challenge CYP's participation**

### **Resources**

- ☐ Time required for planning.
- ☐ Short-term nature of much funding.
- ☐ Lack of training for key adults.

(Adapted from Wright *et al*, 2005)

### **Ethics**

- ☐ Handling of sensitive information.
- ☐ Safety measures and parental consent. CYP's entitlement to confidentiality. Informed consent. Consideration of CYP's mental state.
- ☐ The provision of support should a young person become distressed during interview process.
- ☐ Appropriate methodologies and recognition of the power imbalance between adults and children that may require careful monitoring in research situations.

(Adapted from Alderson & Montgomery, 1996)

### **Organisational Culture & Structure**

- ☐ The nature of organisations (e.g. formality, complexity, bureaucracy and internal politics).
- ☐ Poor participatory practice is frequently cited as an obstacle to participation, as good practice is essential in ensuring that CYP have a positive experience of becoming involved and are able to affect change within the organisation.
- ☐ It is important that whatever practice has been undertaken involving CYP's participation is recognised and shared.
- ☐ Covert organisational cultural barriers.

(Adapted from O'Malley, 2004; Wright *et al*, 2005)

### **Individual Attitudes**

- ☐ Adult attitudes and intransigence.
- ☐ Lack of clarity leading to tokenism.
- ☐ Adults' perceptions and decision-making, including their images of children's capacities, and their self interest in maintaining their own position with respect to children.
- ☐ Practitioners concern about the impact on their work; they may feel that their work will change or even that their jobs will be under threat.
- ☐ Structural barriers include for example formal board meetings during school hours, lack of understanding about what participation means, fear about developing new ways of working, lack of knowledge about how to communicate effectively with young people, lack of opportunities to work directly with young people and develop effective relationships.

(Adapted from Davies & Marken, 1998; Hutton *et al*, 2004; Wright *et al* 2005)

For many campaigners for CYP's involvement, simply hearing their views is a very weak response. It stops short of empowering and involving CYP as partners in developing their services. As noted elsewhere, Wright *et al* (2005) found limited long term developments following CYP consultation. Moreover, this review also found that most studies where CYP were involved at the macro, service level are small and descriptive and thus, it remains unclear as to what extent they can be generalised to local or national concerns. Even more importantly, some concerns have been voiced about the possible 'exploitation' of CYP in these contexts. Allard (1996) notes that children may feel that placing them in situations like conferences and/or meetings may be 'embarrassing or indeed counter-productive'. Therefore, careful dissemination processes on how CYP's views made a difference require solid, detailed planning and discussion.



### 3.5 How can we overcome the challenges?

In order to overcome the challenges Kirby (2002) suggests that CYPs involvement in healthcare can include:

- i) Contributing to *policy dialogue* (doing research, providing information, expressing views, lobbying on the content),
- ii) Contributing to *implementation* (involvement in community-level implementation projects) and
- iii) *Monitoring and evaluation* (assessing whether budgets are getting through to local level, evaluating achievements).

In response to the challenges that exist for organisations when undertaking CYP's participation initiatives, the RCPCH (2005) and Cutler (2003) recommended a number of strategies that can be adopted when developing standards. Standards are outlined in Table 9.

**Table 9. Checklist for organisations for CYP's involvement**

#### **Individual Children and Young People**

- ☐ *Policies* that embed CYP's participation in the organisation's everyday practice.
- ☐ *Budgets* dedicated to participation and involvement of CYP.
- ☐ *Champions* at a local authority level with clear duties and powers.
- ☐ *Structures* that include regional participation co-ordinators to promote organisational change and bring people together.
- ☐ *Specialist staff* supported through peer exchange.
- ☐ *Training* for CYP, adult decision-makers, and participation workers.
- ☐ *Guidance, standard setting and quality assurance systems.* Governmental guidance regarding the involvement of CYP is set out in *Learning to Listen* (CYPU, 2001) and more precise standards are given in *Hear by Right* (Badham, 2005). However, there are also calls for a national kite mark (Cutler, 2003; Cutler & Taylor 2000) to show that an agency has not only listened to CYP, but also that their organisation has changed.
- ☐ *Monitoring, inspection and evaluation.* CYP's participation is rarely subject to external inspection and the benefits appear to be rarely assessed.



Kirby (2002; 2003; 2004) notes that CYP can participate across various macro levels: in small-scale local community forums, by representation at district or regional initiatives, and at national-level consultations or representation at meetings. The timescale of their involvement can vary from participation in one-off research consultations, through to sustained participation over several years. This is applicable to healthcare, as well as the social agenda. However, to implement and enable the involvement of CYP in collective and individual decision-making processes, both adults and young people should be supported in terms of key competencies. This review has drawn on the framework by Wright & Haydon (2002) as presented in Table 10, which was felt useful as it helps practitioners to consider the competencies that may be required to overcome challenges.

**Table 10 Competency framework for CYP's involvement (Adapted from Wright and Haydon, 2002)**

<b>Competencies required by adults</b>	<b>Competencies required by CYP</b>
<ul style="list-style-type: none"> <li><input type="checkbox"/> Understanding what participation means and why it is important</li> <li><input type="checkbox"/> Understanding the potential impact of participation (on children and young people and the organisation)</li> <li><input type="checkbox"/> Opportunity to explore attitudes towards participation and working in partnership with children and young people</li> <li><input type="checkbox"/> Knowledge about different methods that can be used to involve children and young people</li> <li><input type="checkbox"/> Communication techniques that enable the involvement of all children and young people</li> <li><input type="checkbox"/> Responsiveness</li> <li><input type="checkbox"/> Sensitivity to and awareness of the individual needs of children and young people</li> <li><input type="checkbox"/> Opportunity to develop imaginative and creative techniques</li> <li><input type="checkbox"/> Knowledge about how to work with children and young people safely and establish appropriate boundaries for their involvement.</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Understanding what participation means and why it is important</li> <li><input type="checkbox"/> Understanding the potential impact of participation (on children and young people and the organisation)</li> <li><input type="checkbox"/> Opportunity to explore attitudes to wards participation and working in partnership with adults</li> <li><input type="checkbox"/> Knowledge about different methods that can be used to involve children and young people</li> <li><input type="checkbox"/> Opportunity to explore how they would like to be able to participate and what they would like to see changed</li> <li><input type="checkbox"/> Team-building activities that enable the development of such skills as listening, being responsive to others, taking responsibility for specific roles, debating, communicating.</li> <li><input type="checkbox"/> Opportunity to develop confidence in expressing their own views</li> <li><input type="checkbox"/> Skills in presenting own views and views of other children and young people</li> <li><input type="checkbox"/> Skills and experience in relation to specific participation activities.</li> </ul>



On a practical level, Coyne (1998) and Morrow (1999) share examples of establishing rapport prior to the data collection including using drawings to relax the child and clear information leaflets about the project. Their message is clear: researchers should follow what the children want in that particular research situation. Hart & Chesson (1998) also suggest a number of innovative ways to communicate with children including puppet-play, drawing, use of photographs and videos. This is reiterated by Morgan *et al* (2002) who suggest strategies for setting the scene; these include reference to an informal atmosphere, using first names, including 'warm up' activities, having adequate room space, and setting-up arrangements. However, such strategies assume that the adult researcher leads and controls the relationship with the child from the outset rather than a process of negotiation. Hence, this is fundamentally different from a situation in which children are active researchers.

A further challenge is balancing power relationships. Ring (2000, 2003) illustrates how she overcame some of the issues concerning power relationships using conversational interviews, drawings (2D) and photographs (3D) with young children at home and at school. She wished to explore socio-cultural aspects important in a child's life at home and school and felt that seeing the world from the child's perspective was the first step in building the relationship. Others dispute that this can be possible when, from an adult's perspective, the world is necessarily viewed differently from that of the child (Kirby, 1999; West, 1995;1996a; 1996b and 1997).

Overcoming challenge includes the change in policy which in part is being witnessed since publication of the NSF (DH, 2004) and Every Child Matters (DfES, 2004). The National Children's Bureau (NCB) has also been involved in a number of health and social care initiatives to encourage CYP's participation in the development of services; for example CEMACH Child Death Review, PCT Child Health Network, and the National Evaluation of Children's Trusts (NECT). The latter is investigating User Participation Panels between February 2005 and March 2007. Additionally, Action for Sick Children has focused project work around involving CYP, which has culminated in the document 'Principles for involving CYP in Service Planning and Delivery Processes for Hospital Services' (ASC, 2006) and this commissioning of the review here outlined.

One aspect highlighted in many of the studies reviewed was the training and support of personnel to support CYP's involvement (re: participation, communication, skills building). Whilst none included a set out programme of user involvement to share, there were several calls for improved training in both the undergraduate and postgraduate curriculum (Viner & Barker 2005; Beresford & Sloper, 1999; Hart & Cheson 1998). Closer liaison with relevant professionals (such as psychologists) is also advised (Hart & Chesson 1998).



## WHAT ENTAILS GOOD PRACTICE?

### 4.1 Introduction

A number of participatory issues will be drawn together in this section. A sample of projects will be shared which give important insights into how best to involve CYP in healthcare services. Studies reviewed also confirmed the willingness and ability of CYP to give their views about their healthcare, and highlight potential ways to involve them in making individual and collective choices. Attention to CYP's participation reflects the growing importance being attached to involving young service users in decisions about:

- 1) Their own care
- Or
- 2) Wider service planning both in local government and the NHS

### 4.2 '*Best practice*' examples of CYP's involvement and participation

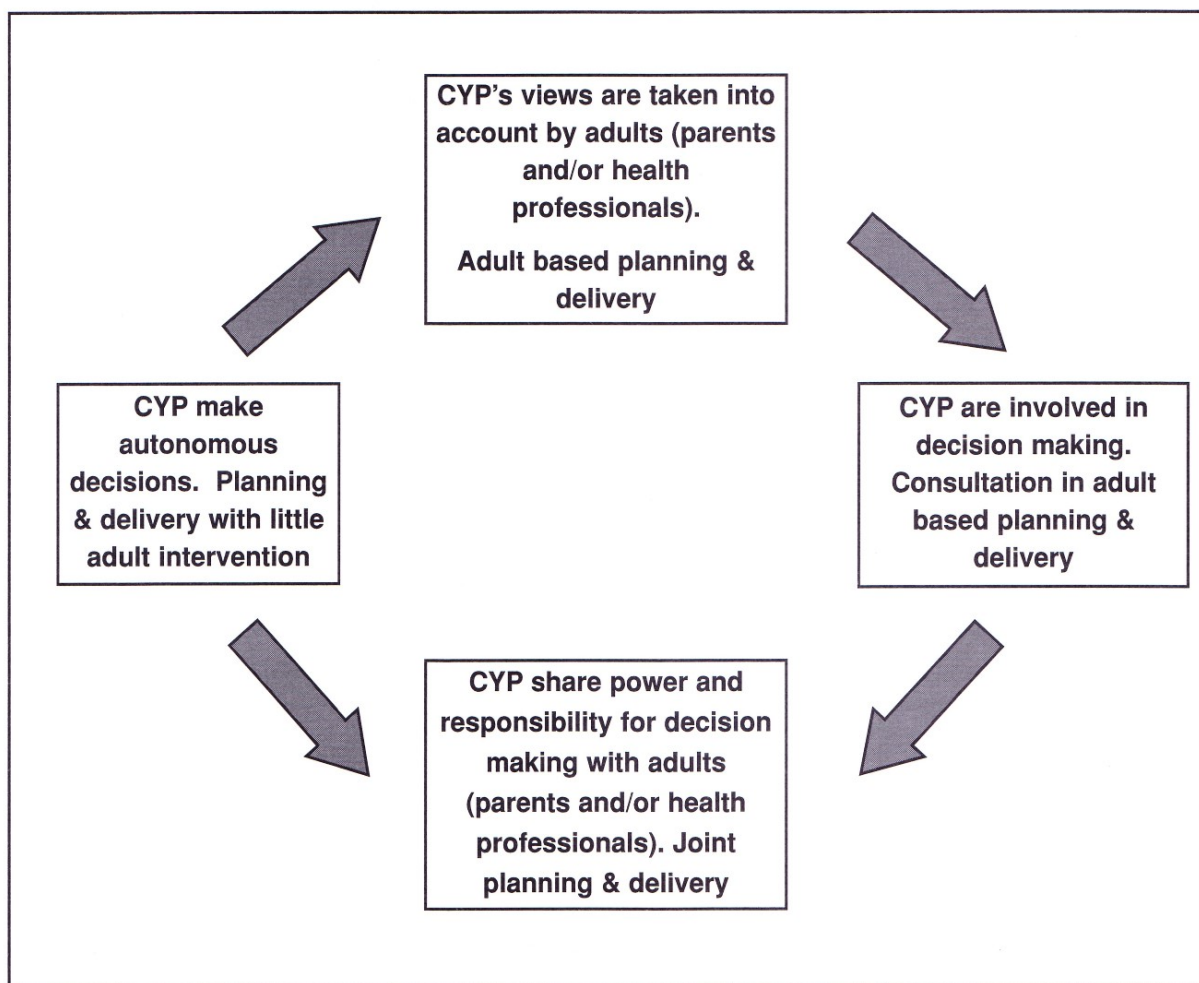
There has been growth in the publication of literature on examining the 'best' methods of involving CYP in involving them in the decision-making within health and social care settings (Sinclair and Franklin, 2000; Shier, 2001; McNeish and Newman, 2002; Kirby and Bryson, 2002). However, other authors argue that, in order for initiatives to be effective, it is necessary for those involved to recognise components which will ensure that 'good practice' can be carried out (Cavet & Sloper, 2004; O'Malley, 2004). Slowly, the literature is moving on from this debate to studying what facilitates a CYP's participatory culture (Kirby *et al* 2003; O'Malley, 2004; Wright *et al*, 2005), and whether participation is sustained and embedded in practice (Kirby & Bryson, 2002; Wright *et al*, 2005).

According to Franklin and Sloper (2004) very little is known about the views of CYP themselves on their experiences of participation, which would, in essence help to inform the development of good practice. More work is therefore required to ensure that participation is meaningful, effective and sustained. However, in seeking to draw lessons from the initiatives reviewed in the literature, one example is that of Save the Children's experience of facilitating CYP participation. O'Malley (2004) discusses the effectiveness of a range of approaches to participation, highlights the challenges, outlines the learning points, and importantly, raises questions about the impact and cost benefits for the CYP's involvement. Drawing on these suggestions from O'Malley (2004), and the findings extracted from the initiatives reviewed in Cavet & Sloper (2004), a number of factors which organisations should consider when facilitating participation have been identified, and were included in Table 9 (Section 3).



One suggestion is to utilise a model of CYP's participation. Such models of participation (Shier, 2001; Lardner, 2001; Kirby *et al*, 2003) highlight the need to understand the term 'participation', and prompt organisations to examine what kind of participation is appropriate. One such popular model, as represented in *Figure 2*, is that of Kirby *et al* (2003) who proposes the adapted model to outline possible levels of participation.

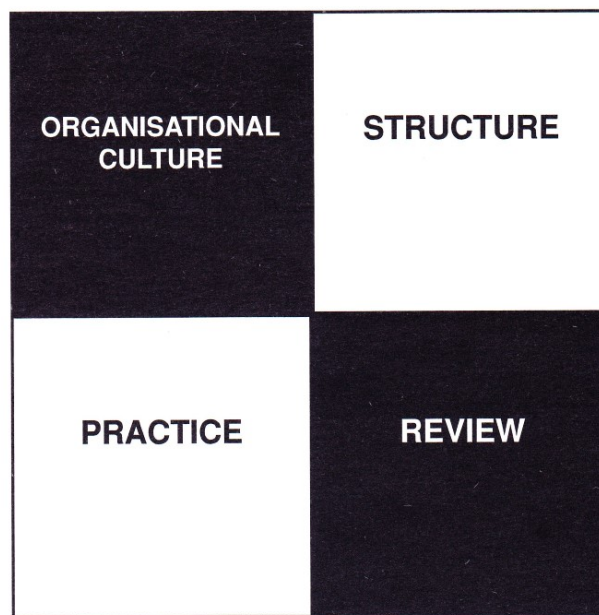
**Figure 2. Suggested model of participation (adapted from Kirby *et al*, 2003 p 22)**



Alternatively, Wright *et al* (2005), advocate developing a culture of participation or 'whole systems approach'. The sections which comprise this model set out the essential steps that need to be taken to implement effective participation, while identifying participation as a flexible and creative process. In developing a 'whole systems approach', Wright *et al* (2005) suggest that organisations develop culture, structure, effective practice and effective review systems. However, they also recognise that developing effective participation across an organisation is not a linear process, and that each of the four elements can be considered separately or added to produce the same outcomes – the change, or improvement of organisations.



**Figure 3. A whole systems approach adapted from Wright et al (2005)**



In terms of the levels of participation, most documents note that participation can vary along a continuum from full involvement and autonomy (participation) at one end, to tokenistic consultation at the other. While some authors see this in hierarchical terms and advocate participation at the highest levels, realistically this can be demanding for both the CYP and organisations in terms of time and resources. As such, most suggest that the level of involvement should be based upon the individual circumstances of individual initiatives and include the preferences of the CYP. However, what all agree, is that CYP should have an active role in service development and this should be based upon a genuine commitment to listen to their views and act upon them.

Furthermore, Hutton (2004) states that even where organisations are committed to a culture of participation, they do not always change their ways of working as a result. Thus, Wright and Haydon (2002) suggest that in order to enable CYP to become active participants, it is essential to plan and develop the necessary structures, which include, staff, resources, decision-making and planning processes. Organisations therefore, may demonstrate a strong cultural commitment to participation, but without an infrastructure to support this commitment, participation cannot properly be sustained. This echoes that of Kirby *et al* (2003), who describe participation as a 'multi-layered concept' suggesting that at least six dimensions should be taken into account when considering participation with CYP.

1. Who will be involved
2. Focus of decision-making
3. Content of decision-making
4. Nature of participation activity
5. Frequency and duration of participation
6. Which CYP are involved



### 4.3 Participation in practice

A number of studies reviewed here present clear examples of how developing such structures can aid effective CYP's participation in various aspects of service development and delivery. We presented specific examples in Section 3.2. (See also Table 6). We have stressed in several sections that in order for CYP to become involved, practitioners need to be able to work in a way, which enables participation and ultimately affects change or improvement within the organisation. Essentially, therefore, they need to be aware of the benefits of participation in order to assist this process. Wright *et al* (2005) state that poor participatory practice, is frequently cited as an obstacle to participation, as essentially, good practice is essential in ensuring that CYP have positive experiences of becoming involved and are able to affect change within the organisation. Table 11 summarises practical advice on how CYP can be involved in order to establish effective participation.

**Table 11. Suggestions to assist the involvement of CYP in practice**

#### **Establishing an effective practice for participation**

- i) Encouraging involvement of CYP from different age groups and specific groups, including those who are seldom heard such as disabled and BME CYP, those in rural areas, those who are homeless, asylum seekers and refugees.
- ii) Ensuring safe participation of CYP.
- iii) Creating a climate for participation.
- iv) Using flexible and creative approaches relevant and appropriate for the CYP.
- v) Understanding the different mechanisms for involving CYP in both the operation and the strategic development of an organisation, as well as individual decision-making processes.
- vi) Provide training opportunities for both practitioners and CYP to develop the necessary skills, knowledge and experience.
- vii) Build in reward mechanisms including feed back and evaluation.

The review aimed to also draw out any 'best' examples of CYP's involvement in terms of healthcare services. Whilst a range of 'grey' and published examples were available it was decided to only include those that were readily available (i.e. published); those with solid principles of involvement as outlined in the review and those which related to health and social care settings (*See also Section 3.2*). Consequently, this is not an exhaustive list but rather key available examples. Whilst we have drawn on key references throughout the review text, we have also outlined for the reader to review in Table 12, the key findings.



**Table 12. Specific Examples of CYP's positive involvement in healthcare services**

Name	Sample	Methods/Aims	Key findings
<b>Experiences of Hospital</b>			
Carney et al (2003)	213 school children (7-17 yrs) in two paediatric wards of a DGH were given four questionnaires.	<ol style="list-style-type: none"> <li>1) Verbal Structured</li> <li>2) Verbal Unstructured (story or poem of experience of hospital)</li> <li>3) Visual Structured (children to insert speech into the bubbles provided on 5 pictures)</li> <li>4) Visual Unstructured (drawing of picture of experience of hospital)</li> </ol>	<ol style="list-style-type: none"> <li>1) Hospital environment identified as the most important feature of stay by 52.1% of sample</li> <li>2) Physical environment was more likely to be important to YP who commented on TV &amp; games suggesting wanting to maintain continuity between hospital and home</li> <li>3) Overall, the most information was gained from verbal, structured questionnaire</li> </ol>
L4A (1990)	Staff, CYP & Parents were consulted regarding plans for a new Children's Hospital in Derbyshire.	Workshops	<p>Areas of consideration arose:</p> <ol style="list-style-type: none"> <li>1) Identity</li> <li>2) Atmosphere</li> <li>3) Welcome/reception area</li> <li>4) Play</li> <li>5) Outside environment</li> <li>6) Access</li> <li>7) Environmental Control</li> <li>8) The role of Art</li> </ol> <p>CYP wanted:</p> <ul style="list-style-type: none"> <li>• Reception areas to be welcoming &amp; spacious</li> <li>• Age appropriate facilities for play and recreation <i>including</i> those for the disabled and those with learning disabilities</li> <li>• A view of green spaces and gardens</li> <li>• Less fluorescent lights</li> <li>• Better facilities for parents</li> </ul>
Anshen Dyer (1999)	On behalf of Great Ormond Street Hospital, to listen to experiences of CYP who used the hospital, to obtain views about the whole hospital & campus.	Three concept groups undertaken including one with CYP, who participated in question and answer sessions, and drew pictures of the way they would like any part of the hospital to be.	<p>Concluded that the key design considerations for CYP should be:</p> <ul style="list-style-type: none"> <li>• A welcoming environment</li> <li>• Evidence of activity</li> <li>• Use of colour &amp; space</li> <li>• Natural daylight</li> <li>• A view of green spaces</li> <li>• The need for privacy</li> <li>• Accessibility</li> <li>• Greater use of age appropriate art and décor</li> <li>• The need to be segregated from younger children.</li> </ul>



Sharma & Finlay (2003)	57 CYP aged 10–18 were consulted to explore the issues raised in a previous consultation exercise that aimed to obtain views on what CYP considered to constitute the ideal ward. Results were incorporated into the design of a unit for CYP.	Structured questionnaire, with space at end for comments.	<p>52 of the sample had spent &lt;1 week on the ward, and 3 had spent &gt;3. They were generally happy with the new facilities, although some inadequacies were highlighted –</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Décor was dull, and there should be more pictures or posters on walls</li> <li><input type="checkbox"/> 33% felt that there was not enough privacy for telephone calls</li> <li><input type="checkbox"/> 35% were not sure if parental facilities were adequate, while 7% felt it was unsuitable</li> <li><input type="checkbox"/> A greater number of videos and computer games requested</li> <li><input type="checkbox"/> The quality, quantity and availability of food were inadequate</li> </ul>
Cited in Kirby (2003b) Sandwell and West Birmingham NHS Hospital Trust: Two children's hospital units	<p>Adolescents aged 11–18 years; in patients, out-patients and external groups of young people.</p> <p>The project aimed to create an environment that meets the needs of young people to make the service more patient-focused and patient-driven.</p>		<p><b>Ways young people involved</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Young people involved in admission process.</li> <li><input type="checkbox"/> Young people involved in decisions about their own treatment.</li> <li><input type="checkbox"/> Satisfaction surveys on service.</li> <li><input type="checkbox"/> Focus groups evaluate the service.</li> <li><input type="checkbox"/> User Group Assessments: On a quarterly basis an appropriate group is invited to the Unit to comment on the broader aspects of service provision, along with parents and staff.</li> <li><input type="checkbox"/> External young people involved in evaluating the service.</li> <li><input type="checkbox"/> Meeting with young people to review the quarterly report and validate results.</li> <li><input type="checkbox"/> Feedback received from child and family on discharge of child.</li> </ul> <p><b>Example of outputs</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Professionals more 'in tune' with young people's needs, meeting their expectations.</li> <li><input type="checkbox"/> Greater compliance with treatment by self-harmers and the chronically ill because they have been involved.</li> <li><input type="checkbox"/> New design for teenage room.</li> <li><input type="checkbox"/> Introduction of sanitary towel machine.</li> <li><input type="checkbox"/> Reassured and confident about medication and condition through being involved in process with medical professionals.</li> <li><input type="checkbox"/> More control over individual drug use in hospital and at home.</li> </ul>
Moules (Ed) (2004) Whose quality is it?	<p>Young people report on a participatory research project to explore the involvement of children in monitoring quality of care in hospital.</p> <p>A group of young people asked children from years 5, 6 &amp; 9, what aspects of hospital care they would use to rate 'good' or 'bad' and whether they should be asked their views.</p>		<ul style="list-style-type: none"> <li><input type="checkbox"/> Six young people began to meet to take the project forward, to explore if and how CYP could be involved in clinical audit.</li> <li><input type="checkbox"/> They began helping with the analysis of the interviews which had been stated; they identified 5 important factors which contributed to care being rated as excellent: privacy; good technical skills; explanations; choice and friendly staff.</li> </ul>



Hallstrom & Elander (2004) Decision-making during hospitalisation: parents and children's involvement	The research project aimed to explore what kind of decisions were made and how these decisions were made, during a child's hospitalisation. During a 9-week period, 24 children and their parents were followed during the course of events at the hospital. In total, 135 hours of observations were made and analysed in to steps.	<input type="checkbox"/> Most of the decisions were of a medical nature, and commonly decisions were made in consultation with those affected by the decision. Although one or more persons protested in 83 of the 218 described situations, decisions were seldom reconsidered. <input type="checkbox"/> It was concluded that CYP were usually involved in the decision-making process, however few made decisions themselves and even if they disagreed with the decision made, few decisions were reconsidered.
Boylan (2004)	Children's Voices Project – Feedback from CYP about their experience and expectations of healthcare. 0-17 years old	Postal questionnaire
<b>Transition into Adulthood</b>		
France, A (2000) Youth Researching Youth: The Triumph & Success Peer Research Project (Joseph Rowntree Foundation)	'Triumph & Success' project ran for 2 years in Sheffield. Using 8 young people between 15 – 21 from different social & economic backgrounds to help undertake research on youth transitions in Sheffield.	Interviews and questionnaires designed by the young people themselves. The project was run by a team of youth workers and supported by professional researchers from a local university. The young researchers undertook a survey with 750 peers, and face-to-face interviews with 60 CYP from a range of backgrounds across 4 wards in Sheffield. This included hard to reach groups and CYP from ethnic minorities.
		<p>The project succeeded in:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Implementing a peer research project that undertook all the research tasks planned.</li> <li><input type="checkbox"/> Engaging and training young people as peer researchers.</li> <li><input type="checkbox"/> Giving young people a voice in the design and implementation of research on young people.</li> <li><input type="checkbox"/> Producing recommendations for policy-makers and practitioners about youth transitions, especially in terms of local circumstances.</li> <li><input type="checkbox"/> Bringing major personal benefits to the young people involved.</li> </ul> <p>Using peer researchers to influence the research helped</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Shape the way that questions were constructed and the themes that the research should explore.</li> <li><input type="checkbox"/> Influence the language of the research, finding a more 'youth friendly' way of constructing research methods.</li> <li><input type="checkbox"/> Contact hard-to-reach groups in the research process.</li> </ul> <p>The project did encounter some problems</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> The level of influence the young people had was limited because peer researchers were engaged <i>after</i> the questions to be investigated had been selected. Greater influence could have been achieved if they had been involved earlier.</li> <li><input type="checkbox"/> Analysis and contribution to broader debates about youth transitions was limited.</li> </ul>



Care Action Team (CAT), Hampshire Social Services (Cited in Wright et al, 2005)	The Care Action Team is a group of young people who are, or who have been in care. They work alongside members and officers of Hampshire County Council to improve services offered to CYP in and leaving care  Seven care-experienced core members aged 15-21: females and 2 males. Majority of users were white.	<input type="checkbox"/> Project is young person-led and facilitated by two previous members who are now employed by the council. The team holds a general meeting once a month and meet outside this to focus on specific pieces of work such as consultations, inspections and training provision. <input type="checkbox"/> The CYP train and give presentations to professionals who work with young people; advise and challenge managers on decisions relating to the services that affect young people; promote the importance of 'true' consultation with young people and work to change the stereotype of young people in care. <input type="checkbox"/> A health needs schedule was developed with CYP for use with their peers and a group of care leavers were trained as peer interviewers.
Broad & Saunders (1998) Involving young people leaving care as peer researchers in a health research project: a learning experience.	Main aims of the project were to identify the health needs of CYP leaving care, to explore the health experience of young care leavers, and to suggest ways in which health service provision to this group might be improved. A group of CYP were involved as members of the research steering group and as researchers.	<input type="checkbox"/> The study has potentially wide reaching implications across primary and secondary healthcare, and across agencies providing services to CYP in terms of facilitating a person's transition through adolescence and into young adult life. <input type="checkbox"/> Participants suggested key issues to address when developing services for CYP including staff consistency, civility, clinic structures which help a person navigate the healthcare system, information age-specific, and support in relation to a range of health, emotional, social and developmental needs.
Dovey-Pearce et al (2005) Young adults suggestions for providing developmentally appropriate diabetes services – a qualitative study	This qualitative user-involvement study aimed to describe and understand the considered opinions of 19 young adults with diabetes who were receiving secondary care services about the provision of diabetes services for CYP.  Findings were gathered using semi-structured interviews and focus group methods.	
<b>Miscellaneous</b>		
Health Through Action Project – Peer Support Groups, Barnardo's  Cited in Wright et al (2005)	This project provides planning, support and bereavement service to CYP affected by HIV and their carers. The peer support groups are young person-led.  There are two peer support groups – one for 10-15 year olds, and one for 16-18. All members are either infected or affected by HIV. There are approximately 13 group members. More than half are male, and there is a broad mix of minority ethnic groups.  Peer support groups are led by young people. Evaluation forms are used at the end of each group session to inform activities for future ones.  They have been encouraged to identify issues to campaign on and have been successful in raising awareness of HIV and highlighting related issues.	<input type="checkbox"/> The group have raised awareness of HIV/AIDS through the production of a video for conferences, schools and practitioners, leaflets and postcards sent to family planning clinics and a public display for World Aids Day. <input type="checkbox"/> The group have been instrumental in campaigning for the forthcoming establishment of a support group for young carers. <input type="checkbox"/> The group have been involved in writing job descriptions and recruiting staff. <input type="checkbox"/> An increased understanding of HIV 'at their own pace' has allowed the support group members to grow in confidence and develop social relationships. <input type="checkbox"/> The project has produced the following documentation to evidence the development of participation: <ul style="list-style-type: none"> <li>- Service Business Plan 2004-5, outlining project aims</li> <li>- Activity/group planning sheet</li> <li>- Group publicity</li> <li>- Evaluation of group activities (staff and child)</li> </ul>



Harker et al 1999 (Cited in Cutler, 2001)	'A Voice for Black Young People in the NHS in Sheffield' used 16 young people aged 16-25 and aimed to establish a forum for black young people to influence local decisions which affect their health.	Forum of young people.	<p><input type="checkbox"/> Based in the Social and Community Development Section of a health authority. Training and support is provided in advocacy skills. A 'rough guide to health' was produced and the group provides input into a city-wide strategy for young people in order to ensure that the health needs of young black people are met. The forum was set up following a black young people's conference in Sheffield.</p>
Lambeth/Southwark/ Lewisham Health Action Zone Cited in Cutler (2001)	'Child to Child' ran projects in school settings with 9-12 year olds	<p>The role of the adult facilitators was to guide the children through a series of stages:</p> <ol style="list-style-type: none"> <li>1) Group work</li> <li>2) Brainstorming</li> <li>3) Select and Prioritise</li> <li>4) Finding out more</li> <li>5) Taking Action</li> <li>6) Review &amp; Reflect</li> </ol>	<p><input type="checkbox"/> An approach to health promotion/community development that encourages and enables CYP to play an active and responsible role in their health.</p> <p><input type="checkbox"/> Children identify those issues that they feel are in the most urgent need of attention; they find out more about these issues, come up with a plan about how to make things better and then they do it.</p>
Imagine London (Cited in Cutler, 2001)	A project set up by the King's Fund to involve young people in decision-making about the future of London with a special reference to healthy futures. Major one-day events on consultation themes are carried out and their views are directly presented to the relevant London decision-makers as well as being written up and circulated to the London health community.		<p>The project identified the following obstacles to involvement:</p> <ol style="list-style-type: none"> <li>1) Public involvement is one of many priorities within the NHS – many organisations would like to involve the public but feel they lack the time, expertise and resources to do it properly.</li> <li>2) There is a perception that most CYP are healthy and do not use the NHS services frequently – so why ask them to get involved in planning?</li> <li>3) The NHS is a highly professionalized (and hierarchical) organisation – medical professionals will need time to adjust to new ways of working and greater public input.</li> <li>4) Some groups are beginning to feel 'over-consulted' particularly young carers and young people in care. There needs to be a clear rationale and purpose for working with young people – linked to targets and evaluations.</li> <li>5) Most projects are still in the stage of asking young people what they think rather than involving them fully in planning.</li> <li>6) Increasing youth participation in the NHS planning has implications for people's working styles and patterns of work.</li> </ol>



<p>Cited in Kirby (2003b) Skye &amp; Lochalsh Young Carers Project</p>	<p>Small voluntary organisation working in a remote rural area with 40 CYP aged 5-18 years.</p> <p>In partnership with young carers, local organisations and service providers, the project aims to raise awareness and improve local support. Purpose is to encourage decision-making.</p> <p>The CYP participate at all levels of the organisation, choosing how they wish to be involved.</p>	<p><b>Ways young people were involved</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Young carers choose the level of involvement which suits them.</li> <li><input type="checkbox"/> Young carers decide what they want to be involved in.</li> <li><input type="checkbox"/> Working/challenge games to promote decision-making.</li> <li><input type="checkbox"/> Young carers fill in questionnaires which they have asked for and helped to design, and which are used to inform schools of the young carers' situations.</li> <li><input type="checkbox"/> Respite outings where individual needs are discussed with young carer.</li> <li><input type="checkbox"/> Weekly supported group meetings x 3: a primary group, a secondary group and an additional needs group, with flexibility to move between groups as stepping stones to peer level.</li> <li><input type="checkbox"/> Young carer focus group meetings.</li> <li><input type="checkbox"/> Young carers on Skye and Lochalsh Community Care Forum Management Committee.</li> <li><input type="checkbox"/> Young people involved in creating internal policies.</li> <li><input type="checkbox"/> Young carers devised guidelines for hospital on how health professionals should approach/support them.</li> <li><input type="checkbox"/> Young carers involved in input to the Highland's Children Service Plan and Carer's Bill.</li> <li><input type="checkbox"/> Young carers involved in the development and training of front line care staff;</li> <li><input type="checkbox"/> Skills development training is organised and delivered to meet young carers' self identified needs e.g. First aid.</li> <li><input type="checkbox"/> Moving and handling, stress and anger management and social skills.</li> <li><input type="checkbox"/> Produced the Young Carers 'Hands On' Information Pack.</li> <li><input type="checkbox"/> Take part in evaluation report through questionnaires.</li> <li><input type="checkbox"/> Involved in activity evaluations across the service.</li> </ul> <p><b>Example of outputs</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Workers have gained more knowledge from the young carers about working with this client group.</li> <li><input type="checkbox"/> A higher response to questionnaires for young carers and their families, and therefore more information on the needs of the service users has been gained.</li> <li><input type="checkbox"/> Young carers have trust and confidence in the project which benefits the development of the project.</li> <li><input type="checkbox"/> Care attendants felt more able to understand the needs of young carers after training course.</li> <li><input type="checkbox"/> Young Carer Guidelines distributed and introduced to NHS providers.</li> <li><input type="checkbox"/> Young carers influenced the Highland's Children Service Plan and Carer's Bill;</li> <li><input type="checkbox"/> 'Hand On' Information Pack is being used locally and has now been rolled out across the Highlands.</li> <li><input type="checkbox"/> Recognition of gaps in service provision for young carers.</li> <li><input type="checkbox"/> Increased support from guidance counsellors.</li> <li><input type="checkbox"/> Increased feeling of control.</li> </ul>
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Cited in Kirby (2003b) All Parliamentary Group for CYP in and Leaving Care, London.	CYP in care or leaving care in the UK attend group meetings, input into the agenda of meetings and showcase their work. The purpose of the participation is to ensure that the voices of CYP with experience of public care are heard throughout Government.		The group played a part, along with others, in successfully lobbying for statutory duties of local authorities to extend to provide for young people up to 21 years. Previously, the Leaving Care Act only supported young people up to 18 years.
Cited in Kirby (2003b) Collingham Gardens Child Psychiatric Unit: London	Children aged 5 to 13 years with complex mental health needs, requiring in-patient assessment involved in order to discover CYPs perceptions of the purpose of their admission and factors which enhance or decrease their motivation to engage in therapeutic work.	Research interviews held with the CYP.	<p>Example of outputs:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Increased staff understanding of children's experiences of their treatment. In particular the findings highlighted children's expectations of passivity in their own treatment and how this can undermine therapeutic engagement.</li> <li><input type="checkbox"/> Increased commitment to involve children more in their own care (more dialogue with children about their treatment, increasing children's role in their own care planning and goal setting) and to consider ways to develop children's role in influencing the service;</li> <li><input type="checkbox"/> The research provided supporting evidence for staff views about outreach support, which is useful for funding purposes;</li> <li><input type="checkbox"/> Identification of the need for support for children entering hospital from community services, although this has not yet been disseminated or actioned.</li> </ul>
Cited in Kirby (2003b) Contraception and Sexual Health Project (including Zone Youth Project, KISS and Club One), Nottingham	<p>Groups of CYP aged 12-25 years (majority 13-19), predominantly white, but also African-Caribbean. Purpose of participation to reduce rate of conception through innovative ways of engaging with socially excluded CYP. CYP involved in service development, delivery, decision-making and the monitoring and evaluating of services. All projects have accredited peer education and volunteering opportunities.</p>		<p><b>KISS Project:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 700 young people consulted about setting up a new sexual health service in two secondary schools; 15 young people involved in the development of the service;</li> <li><input type="checkbox"/> A multi-agency steering group (which included young people) oversaw the project.</li> <li><input type="checkbox"/> Developing resources and publicity materials;</li> <li><input type="checkbox"/> Involved in discussions around funding and sustainability;</li> <li><input type="checkbox"/> Interviewing staff;</li> <li><input type="checkbox"/> Supporting evaluation processes so that they are young people-friendly.</li> </ul> <p><b>Zone Project:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Decisions on which projects are undertaken by young people;</li> <li><input type="checkbox"/> Setting up events – the World Aids Day party, for example;</li> <li><input type="checkbox"/> 3 young people are active members of the management committee;</li> <li><input type="checkbox"/> 6 young people run the Creative Youth Arts Company within Zone;</li> <li><input type="checkbox"/> Young people plan residential and other trips;</li> <li><input type="checkbox"/> Young people influenced the drug and alcohol policy;</li> <li><input type="checkbox"/> Articles and features in the Pulse Newsletter written by young people at Zone.</li> </ul>



		<p><b>Example of outputs</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Increase in young people's access to contraception and sexual health services;</li> <li><input type="checkbox"/> Greater choice, particularly for those who are least likely to access other services and who are highlighted as high-risk target groups by the Teenage Pregnancy Unit;</li> <li><input type="checkbox"/> Reduced waiting times, as a result of drop-in facilities;</li> <li><input type="checkbox"/> Early evaluation indicates that long-term outcomes will demonstrate an overall improvement in the sexual health of the young people within these communities;</li> <li><input type="checkbox"/> Meeting the needs and priorities of young people more effectively because of better understanding of needs;</li> <li><input type="checkbox"/> Young people report increased skills, confidence, self-esteem, knowledge, and ability to make positive choices;</li> <li><input type="checkbox"/> Improvements in the perception of young people in the local community.</li> </ul>
Triangle, Sussex Cited in Wright et al (2005)	<p>A specialist childhood disability organisation providing training and consultancy to individuals and organisations throughout the UK, and outreach support to CYP in South of England.</p> <p>All their work is with and on behalf of disabled children, and consultation with CYP is built in both internally, through consultation groups to inform their work, through a specific consultation work for other organisations.</p> <p>Three internal consultation groups divided by age (between 9-25 years). Approximately 40 regular members.</p> <p>The majority (80%) of consultation work engaging CYP outside these groups. Through this, Triangle has consulted with more than 1,200 disabled CYP across the UK.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Triangle involves CYP in a range of decisions – from how the groups are run and what services the organisation should develop to staff recruitment. All work undertaken for external organisations is done with the commitment of the commissioners to take action on those issues raised through the work.</li> <li><input type="checkbox"/> Younger children are rewarded with vouchers, while older young people are paid either hourly, or per session. A participation budget incorporates travel expenses, support costs, venues, resources and staff time. The two older consultation groups manage their own budgets.</li> <li><input type="checkbox"/> In addition to the consultation groups, the organisation facilitates consultation with CYP for external agencies on a range of issues and services. These consultations are preceded by contact with the children and their parents to ensure that both understand what the work involves and the importance of participation.</li> </ul> <p>Changes or improvements as a result of CYP participation include</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> A raised awareness (both internally and externally) of disabled children's rights to be involved.</li> <li><input type="checkbox"/> Strong influence by young people on decisions about work.</li> <li><input type="checkbox"/> Impact on national policy through presentations at the House of Commons and at the Audit Commission.</li> <li><input type="checkbox"/> Change in specific practices in services, including bedtimes policy, staff practice, security within residential homes, daytime support, homework policy.</li> <li><input type="checkbox"/> Supported development of consultative groups in other areas.</li> </ul>



		<p>Evidence of outcomes from participation include:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Job descriptions that include reference to the importance of participation.</li> <li><input type="checkbox"/> Recruitment advertisement for CYP.</li> <li><input type="checkbox"/> Outline of training sessions.</li> <li><input type="checkbox"/> Reports on consultations with disabled CYP in different An formats.</li> </ul>
<p>An evaluation of the drop-in service at Wakefield High School Cited in McNeish (1997)</p>	<p>A school nurse had developed a drop-in service one day a week, with the aim to provide CYP with a confidential and independent source of advice on health issues and any other worries they might have. The nurse was keen to find out what the CYP thought about the service, and how it might be improved.</p> <p>With co-operation of school staff researchers and a development worker, CYP were met with during three personal and social educational lessons. CYP participated from all the year groups (ages 12-16). The groups started with some warm-up games and activities and then used a number of exercises to identify the main things that CYP worry about and the sort of support they would need.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> The meetings led to the production of a short list of issues which would need to be explored further with other CYP in order to evaluate the drop-in service.</li> <li><input type="checkbox"/> The group turned these issues into questions for a short questionnaire which they then administered to their own year groups. They achieved an exceptional response rate.</li> <li><input type="checkbox"/> The CYP continued to plan how to feedback their findings and their suggestions for the future of the service.</li> </ul>
<p>Future Visions (1998) Mental Health Foundation</p>	<p>The Mental Health Foundation provided funding and support for 5 User Voice Projects around the UK. All successfully involved CYP in developing an arts and media product.</p> <p>The aims of the projects were to give CYP the chance to say what they think about mental illness and what services and support they need; give health and other professionals the tools they need to help CYP with mental health problems; produce information and materials that can be used to raise awareness of mental health issues within CYP agencies and amongst the public.</p>	



## FINAL DISCUSSION AND CONCLUSION

### 5.1 Discussion

*'The challenges are many, but so are the opportunities' (O'Malley, 2004)*

Over the last decade there has been an increased, emphasis in all four countries of the U.K. about the active involvement and participation of patients (children, young people and adults) in the decision-making process about healthcare issues that affect them. This has meant that there has been a fundamental shift in official attitudes towards CYP being viewed as needing adult guidance and protection, to being viewed as citizens with rights, and as people who can act to secure these rights themselves. In this way, it is felt that services will be planned that meet the explicit needs of CYP users.

The review highlighted the many positive examples of consultation with CYP using innovative and creative methods. Studies reviewed confirmed the willingness and ability of CYP to give their views about their healthcare, and highlighted potential ways and opportunities to involve them in making individual and collective choices. Despite this, the review also highlighted that published literature and evaluative reports of how CYP were involved in the decision-making process (as full participants) in terms of their own care and wider service planning, and subsequent impact of their involvement, were as yet, scarce. Indeed, we know little about the views of CYP themselves on their experience of participation, which could inform development of good practice.

### 5.2 Recommendations

Several important recommendations were identified by the review:

- Whilst there are many positive examples of CYP's consultation (both published and 'grey' literature), solid evidence of CYP fully participating is limited therefore more work is required to ensure that full participation is meaningful, effective and sustained. Dissemination of that work is thus essential.
- It would also be useful to survey the four countries of the U.K. in terms of the long-term impact of involving CYP in healthcare services. One aspect of this work should be to explore in more depth, a sample of case studies to evaluate the level of involvement of CYP.
- To date, the focus has been on the process of involvement, rather than evaluation of outcomes for either the individual CYP or for services. Innovative ways should be sought to access 'hard to reach' or overlooked groups of CYP, whose needs and lifestyles, make finding representatives very challenging but not impossible.



### 5.3 Conclusion

In conclusion, this report was prepared for, and funded by, Action for Sick Children and presents the findings of an extensive review surrounding CYP's involvement in developing healthcare services. This will form an integral part of their '*Children's Voices*' project. We thus hope that the report is not only a useful background resource for Action for Sick Children members, but will also help to inform subsequent participatory work with CYP. We found that involving CYP in the decision-making and participation of healthcare services was viewed as a positive development and found many innovative examples and suggestions. However, scoping of the literature also highlighted that whilst the techniques for consultation and participation with CYP have progressed, there is still considerable work to be undertaken; not least in evaluating how those who plan and/or deliver healthcare services respond. This is essential if significant change in healthcare services and policy is to be sustained. Consequently, the challenge for the future is to evaluate the extent to which '*Children's Voices*' are actually heard and acted upon in healthcare service planning and delivery.



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