

# **Voices of Children and Young People**

**INVOLVING CHILDREN & YOUNG PEOPLE  
IN THE DECISION-MAKING PROCESSES OF  
HEALTHCARE SERVICES**

A review of the literature



Dr. Jane Coad, Principal Researcher.  
PhD; MSc; BSc (Hons); PG Dip; RGN/RSCN.

Rosie Houston, Research Assistant  
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# Foreword

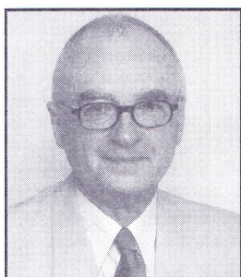
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There is a climate of change in healthcare services towards a more user led service delivery. Over the last decade there has been an ever increasing emphasis on the involvement and participation of patients in the decision-making process. This has resulted in a fundamental shift in the attitudes towards children and young people, moving from needing adult guidance to those of citizens in their own right with their own views.

It is extremely important to obtain the views of children and young people as they are the decision makers of tomorrow. What they say today will be used to make decisions for future planning. But those who obtain the views of children and young people must demonstrate that they have listened to their advice and acted accordingly to validate such decisions.

Using the views of children and young people becomes for adults a real challenge. Reviewing what has happened already through this literature review is a strong basis for effective development in building a platform for the participation and involvement of children and young people in the planning of future services.

A very important publication!



**Professor Sir Al Aynsley-Green**  
*Children's Commissioner for England*



This is an important and very useful publication, drawing together the current literature in this emerging field of practice. The authors and Action for Sick Children are to be congratulated.

The importance of involving children and young people in decisions about their health and healthcare cannot be over-emphasised. However, doing this well can be a challenge. Policy is clear, as emphasised in the National Service Framework for Children, Young People and Maternity, attitudes have changed but there is more to do to turn the vision into reality, particularly including the many under represented groups.

One of the biggest challenges in children's healthcare is persisting inequalities and we need to ensure we reach out to those most in need.

An additional task is covering our whole age range. Using appropriate techniques even very young children can be consulted and involved in decisions on a one to one basis or about their condition or their services. They have views about staff, the environment, their medicines and many other areas. We can improve their care by hearing their voice. Children are willing and able, when given the opportunity and the needs of adolescents, in particular, would be better served if we listened carefully and involved them more.

Much work needs to be done on the evaluation of outcomes of this work, not solely on how to involve children but a good start has been made. Research and this publication shows us how far we have come and how far we have yet to travel. Read it and learn more, practice must change if we are to deliver the improved outcomes children, young people and their families deserve.



**Sheila Shribman**

*National Clinical Director for Children, Young People  
and Maternity Services.*

# “An Action for Sick Children Vision”

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Why do we need a review of literature surrounding the views of children and young people?

Action for Sick Children was formed over forty years ago to champion the cause of sick children, young people and their families, working hard to improve the services and attitudes for those children and young people when they are unwell – in hospital, at home and in the community. Our aim is to ensure that healthcare in the UK meets the unique needs of all children, young people and their families.

Action for Sick Children was delighted when the Government took the initiative to develop the Children's National Service Framework. We were also pleased to contribute through membership of various External Working Groups. The overall direction of travel fits well with Action for Sick Children objectives.

In 2005, Action for Sick Children was awarded a Section 64 grant from the Department of Health to enable the charity to investigate how and where children and young people were being approached to establish their input into future healthcare services. The Steering Group decided to commission Dr Jane Coad to carry out a literature review in order to establish what has already been achieved. The findings have been so interesting that Action for Sick Children has taken the step of publishing this review. This will form the basis for the research project to move forward.

We are indebted to the Children's Commissioner for England, Professor Sir Al Aynsley-Green and to Dr. Sheila Shribman, National Clinical Director for Children for endorsing this “review” and to the Department of Health for the funding. The next phase of the project will aim to establish how these views of children and young people are being gathered and how these views are being taken into consideration when planning future services.

***Pamela A. Barnes***

*Chairman – Action for Sick Children*



# Steering Group

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## Abbreviations and Acronyms

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ASC	ACTION FOR SICK CHILDREN
CAMHS	CHILD AND ADOLESCENT MENTAL HEALTH SERVICES
CYP	CHILDREN & YOUNG PEOPLE
BMA	BRITISH MEDICAL ASSOCIATION
BME	BLACK AND MINORITY ETHNIC
DfES	DEPARTMENT FOR EDUCATION & SKILLS
DH	DEPARTMENT OF HEALTH
ECM	EVERY CHILD MATTERS
HTR	HARD TO REACH
NSF	NATIONAL SERVICE FRAMEWORK
NHS	NATIONAL HEALTH SERVICE
MORI	MARKET & OPINION RESEARCH INTERNATIONAL
NAO	NATIONAL AUDIT OFFICE
ONS	OFFICE OF NATIONAL STATISTICS
RCN	ROYAL COLLEGE OF NURSING
RCPCH	ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH
UK	UNITED KINGDOM
UN	UNITED NATIONS
UNCRC	UNITED NATIONS CONVENTION OF THE RIGHTS OF THE CHILD
WHO	WORLD HEALTH ORGANISATION

*\* Keys to other abbreviations are provided where appropriate*

# Executive Summary

---

## Context and Aims

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 children and young people (**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 purpose of this was to undertake an initial scope of the literature of U.K. children's services in the light of the Government's user involvement agenda. It was envisaged that this would highlight priorities and draw upon 'best available published evidence' to help inform future development with respect to health services for children and young people up to the age of 18 years.

## Methods

An overview of the literature was undertaken between March and April, 2006 to outline what was already known about CYP's involvement in the decision-making process of healthcare services. A multi-method approach was employed and included:

- 1. A review of published literature pertaining to CYP's decision-making process of healthcare services.*
- 2. A review of relevant 'grey' literature*
- 3. A review of established research and practice networks, via personal contacts*

A theoretical framework was used to collect data from both the *micro* (individual) and *macro* (collective) perspective. Within the framework, data was reviewed in relation to the following research questions:

- 1. What evidence is there that CYP are participating in decision-making?*
- 2. What are the benefits of CYP participating in decision-making?*
- 3. What are the barriers to CYP participating in decision-making?*
- 4. How can we overcome the challenges?*

Finally, a section on developing a model for participation was outlined including offering real examples of published literature where 'best practice' of CYP's involvement was evident.



## **Key findings**

### ***Individual CYP***

Almost all of the documents accessed provided a rationale for why CYP should be involved in making decisions about services. Further, the value of participation of CYP in public decision-making is now well accepted, and is recognised in the standards set in the Department of Health (DH) National Service Frameworks (NSF) (DH, 2003a; DH, 2004). The review also highlighted that whilst there were many positive examples of individual CYP involved in consultations, there was limited critical evaluative, published literature to demonstrate that they were full partners (or fully participating) in terms of healthcare services. Instead, it was found that most communication and decision-making typically had occurred through parent-provider interaction and/or adult health carers. There was also limited published information found which sought to evaluate how CYP's views had impacted on healthcare services and care. However, many positive examples of consultations were found in the 'grey literature' (such as conference papers, web-based and verbal communication) so it is hoped that in the future publications will emerge that reflect CYP's involvement in healthcare services more fully.

### ***Collective issues***

There were interesting, but mixed findings, surrounding the involvement of groups of CYP across organisational and service delivery. Examples of groups drawn on included acute in-patients; transitional care, community settings; CYP with a mental health problem; respite care; BME groups; the under-fives; young people, disabled CYP; long term illness and asylum seeking CYP. Overall, it was found that many groups remained under-represented. Most of the literature suggested that the level of CYP's involvement should be based upon the circumstances of individual service initiatives and include the preferences of the CYP as a group. What was agreed 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. The review found several practical guides to participation. However, the reality of using these in health-care settings with CYP and subsequent evaluation to date was limited.

### ***'Best practice' examples***

There has been a growing publication of literature on examining examples of 'best practice' of involving CYP in the decision-making within health and social care settings. The review includes an overview of specific CYP groups and a sample of projects were drawn upon. It would be useful to review this sample in more depth, as case studies, but this would go beyond the remit of this review.

## **Discussion & recommendations**

The review highlighted the many positive and exciting 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 to involve them in making individual and collective choices.

Despite this, the review also highlighted that evaluative reports of how CYP were involved in the decision-making process (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.

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 was limited in the published and available literature. 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 study in more depth, a sample of case studies, to explore the level of involvement with the aim of extracting positive messages about CYP involvement.
- 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.

These recommendations are essential if CYP's involvement in health services and healthcare 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.



# Section 1

---

## Introduction

### 1.1 Context

In the last 10 years of welfare policy, in each of the four UK countries, there has been an increased emphasis, that there is a need for greater involvement by patients and the public in the planning, design and management of health and social care services. This has given rise to a plethora of consultations, audits and research projects, seeking their input. With increasing empowerment, the representation of people who are vulnerable, marginal or hard to reach in our communities is thus increasingly essential as part of achieving a more inclusive society. Where governments seek to establish greater plurality in the provision of health services, with a broader range of providers from private and not-for-profit sectors, the need for vulnerable groups to be represented in the governance of health service organisations will increase.

Vulnerable groups include children and young people (CYP), which was the focus of this review. In terms of CYP *user involvement*, most notably this commenced with the publication of Article 12 of the United Nations (UN) Convention of the Rights of the Child (UNCRC, 1989), which called for state parties to: *'assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'*. Following this, there has been a torrent of international and national government initiatives, including in the U.K, *National Service Framework for Children, Young People and Maternity Services* (NSF, Department of Health [DH], 2004) and *Every Child Matters* (Department of Further Education and Skills [DfES], 2004). Both of which have flagged up the bringing of CYP's perspectives to bear on all aspects of government policy.

Consequently, web-based link groups such as CRIN (Children's Rights Information Network), CAPA (Children as Partners Alliance) and 4NCPN (4 Nations Child Policy Network) have recorded ways of improving CYP involvement and decision-making (See also Section 2.5). Similarly, within the U.K, children's pressure and information groups (e.g. INVOLVE, Royal College of Nursing; Children's Rights Alliance for England (CREA); Action for Sick Children; Joseph Rowntree; National Children's Bureau; The Children's Society; Funky Dragon; HeadsUp; National Voice; Voices from Care) have also supported user involvement developments. Further, measures to improve communication with CYP have included the establishment of a 'Children and Youth Board', in addition to the appointment of a Minister for Children and Children's Commissioners in Northern Ireland, Wales, Scotland and England. The increase in user involvement across all four UK countries has thus resulted in a huge number of consultations, audits and research projects, all of which aim to involve CYP users and their families to a greater or lesser extent. These groups are united in a firm conviction about the importance of involving CYP in decision-making; an agenda which clearly overlaps with democratisation and citizenship.



One can discern several important trends about the development of CYP user involvement. One trend, echoed in the policy changes noted above, is the development of approaches seeking to involve and explore the views of CYP (Kirby, 1999; Lewis and Lindsay, 2000). New approaches to involving CYP must be therefore considered, however, it is essential to recognise that new challenges are created in the process (Thomas & O'Kane, 1998; Christensen & James, 2000; Lewis & Lindsay 2000; Fraser *et al* 2003; Coad & Lewis, 2004). There is also an increasing commitment that CYP have more opportunities to get involved in the design, provision and evaluation of social, health and public policies and influence services that affect them (or those which they use) in the United Kingdom (U.K.) (CYPJ, 2001; Franklin & Sloper, 2004; Cavet & Sloper 2004a; Stafford *et al*, 2003). Indeed, health and social care services have begun to acknowledge that, when listened to, CYP can play a vital role in the end delivery of services (Wright *et al*, 2005). In this way, it is felt services can be planned that meet the explicit needs of individual and groups of CYP.

However, by virtue of their needs and lifestyles, finding representatives from CYP groups and their carers, can be difficult. This has given rise to concern that, with the growing number of public consultations on health and social care reform, undue pressure may be brought to bear upon people who can least cope with the need to represent their interests (Coad & Twycross, 2006). Equally, the potential for over-representation by those people within these groups who are most articulate and most accessible could lead to a corruption of the democratic process of consultation. Achieving a balance in representation, which reflects the diversity of modern society and the particular protection rights is challenging.

## 1.2 Aims

The purpose of this review was to scope children and young people's (CYP) involvement in the decision-making process of health-care services. A multi-method approach was employed and included:

1. A review of published literature pertaining to CYP's decision-making process of healthcare services.
2. A review of relevant 'grey' literature
3. A review of established research and practice networks, via contact with key stakeholders

As with all scoping exercises, the aim of this study was to map the extent and nature of the literature that currently exists in relation to CYP's involvement in the decision-making process of healthcare services. It aimed to highlight good practice of CYP's consultation to participation and discuss any obvious gaps, rather than to assess the quality of the individual studies identified.



## **1.3 Definitions**

### **1.3.1 Children and young people**

For the purpose of this review, the term children and young people is used to refer to those under the age of 18 years. This is thereby consistent with the definition used by the UN (1989). For the sake of brevity, children and young people is abbreviated as CYP throughout. Where it is necessary to refer to specific age-groups, the following terms are used:

- Infants                      less than 2 years
- Children                    2-10 yrs
- Young People              11-18 years

### **1.3.2 Health**

In accordance with WHO (1980) health is defined in its broadest sense and is taken to be “a state of complete physical, psychological and social well-being and not simply the absence of disease or infirmity”. Health services are therefore defined as those services that address these aspects of well-being.

### **1.3.3 Consultation to Participation**

Boyden and Ennew (1997) state that there are two interpretations of user involvement. It can simply mean taking part, being present, being involved or consulted, or, alternatively, it can denote a transfer of power so that participants' views have an influence on decisions and knowing that one's actions and views are going to make a difference and may be acted upon. Consultation has been defined as ‘a process which requires the commitment to take on board CYP's views and present detailed information back to them’ (Treseder, 1997). Participation, on the other hand, arguably, creates a more active and empowering experience. This idea is supported by Thomas & O’Kane (1998), who state that participation is ‘an ongoing process of children's active involvement in decision-making (at different levels) in matters that concern them’.

To be most effective, it requires information sharing and dialogue between CYP and adults, which is based on mutual respect and power sharing. Genuine participation gives CYP the power to shape both the process and the outcome (Williams, 2004). In this way, participation involves a culture of listening that enables CYP to influence decisions about the services they receive as individuals on a day-to-day basis, as well as how those services are developed and delivered to all CYP who access them (Wright et al, 2005). Franklin & Sloper, (2004) note that the word ‘participation’ has become shorthand for a huge range of activities that involve CYP in some form of decision-making, and the level and nature of participation can vary. Other authors state that participation is not an isolated activity, but a process by which CYP are enabled to influence change within an organisation (Wright et al, 2005).

## 1.4 Methodology of scoping

A multi-method approach was employed and included:

a) A review of the research, policy and literature concerning CYP's participation drawing on data from thorough search of relevant databases: Medline, Barnardo's Library, National Children's Bureau, Action for Sick Children, Social Sciences Citation Index, Blackwell-Science Index, British Nursing Index, CINAHL, DH-Data, EMBASE.

b) Searches were undertaken using the following sets of terms:

Set 1 Children/young people

Set 2 Participation/involvement/inclusion/consult

Set 3 Decision-making/service provision/service delivery

Set 4 Health/healthcare/social services

Set 5 Minority/disabled

As the search terms identified a large number of references, all results were scanned online and only references relating to CYP's participation and involvement were retrieved. It is expected that in any review the work is limited to what is published and what can be accessed during the time frame of the review (two months in this case). Therefore, a review of relevant 'grey' literature was also undertaken (Hart, 2002). This was subject to less rigid criteria and was included if it was deemed to be relevant and informative. This included web searches of organisations working in areas of research and/or practice with CYP using the key search terms as identified above. In addition, we accessed a number of 'grey' literature sources through personal contacts.

As expected, many articles appeared in more than one database. However, only a minority met the selection criteria. Thus, the references of each article were repeatedly drawn upon until saturation was reached.

## 1.5 Framework

It was agreed that a framework first identified by Bronfenbrenner (1979), would be applied to structure the review. This model views individuals within the context of micro and macro influences, but has been adapted since conception (Cooper, 1999; Coad & Shaw, 2006) so that micro issues include the individual, immediate influences on the patient and family, such as individual CYP's development, condition abilities, family relationships and coping mechanisms and the macro issues include collective issues such as philosophies of care, policy, health information, resources and documentation. Sections are thus divided as 'individual' and 'collective' as represented diagrammatically in *Figure 1*. In adopting the framework for this review, CYP and carers will be placed at a central micro or 'individual' level.

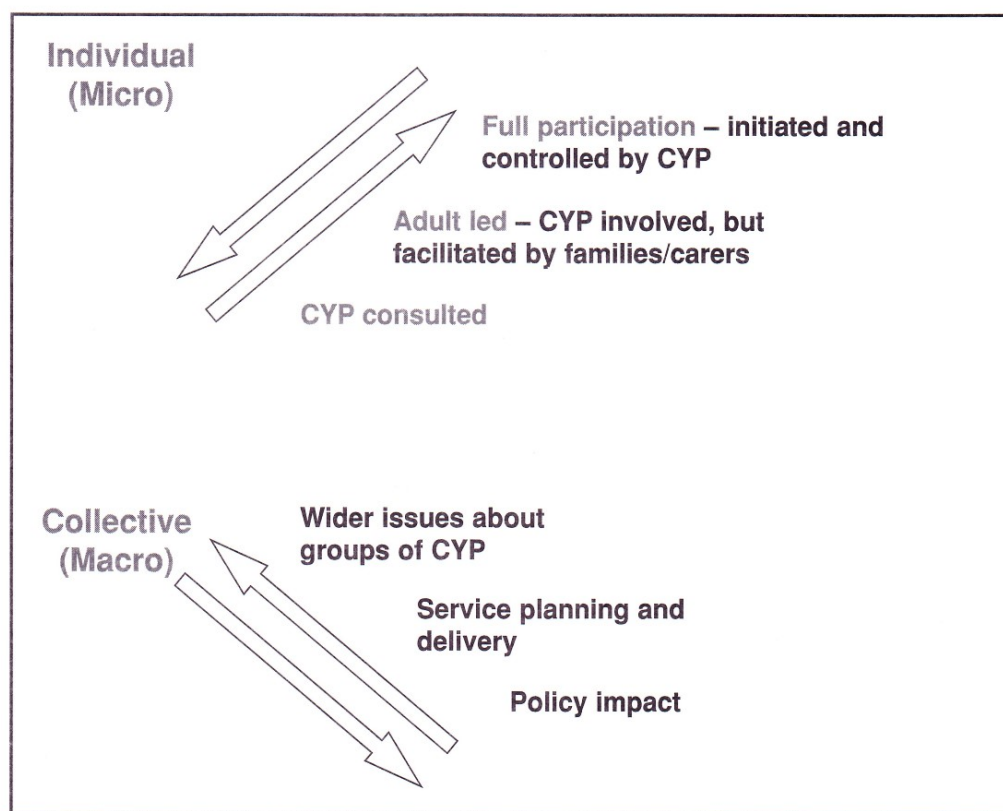


Additionally, the framework will seek to highlight how the macro level or collective issues will impact upon each unit or organisation involving the CYP. In each of the sections of micro, individual and macro, collective issues specific questions relating to both will be used:

- 1. What evidence is there that CYP are participating in decision-making?**
- 2. What are the benefits of CYP participating in decision-making?**
- 3. What are the barriers to CYP participating in decision-making?**
- 4. How can we overcome the challenges?**

Finally, a section on developing a model for participation will be outlined including offering real examples where 'best practice' of CYP involvement is outlined.

**Figure 1. Framework for the review**



Adapted from Coad & Shaw, 2006

## Section 2

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### INDIVIDUAL ISSUES (MICRO) OF CYP DECISION-MAKING IN HEALTHCARE

#### 2.1 Background

It is only recently that standards for patient involvement have made specific references to children and young people (CYP). This has been most clearly articulated in the NSF for Children, Young People and Maternity Services (DH, 2004). These standards require services to *"Give children, young people and their parents increased information, power and choice over the support and treatment they receive, and involve them in planning their care and services"*. Giving CYP the opportunity to be involved in meaningful decision-making and participation within health services therefore represents a significant change in policy and practice. Indeed, *"Children are one of the most governed groups by both the state and civic society"* (Hill *et al.* 2004) and have been traditionally regarded as lacking the social or cognitive competence to make informed decisions about their lives. Additionally, the importance of listening to CYP's views is also a 'legal' requirement, recognised in both the Children's Act (1989) and the UNCRC (Article 12).

Unfortunately, however, while patient consumerism in the NHS is increasingly recognised, the concept of CYP as consumers with fundamental rights has received less acceptance (Aynsley-Green *et al.* 2004; Hart & Chesson, 1998). Instead, it has been suggested by Hart & Chesson (1998) that parents and carer (or providers) assume they know best. Whilst, this approach has been largely motivated by a wish to protect, the views of adults do not necessarily represent those of CYP. Indeed, Beresford, in 1997, noted that parents and health professionals were often unreliable proxies. It may be in this current drive that this has improved since the late 1990's but a marginalisation of CYP's individual views has occurred never the less. Offering CYP real involvement in healthcare service planning is therefore seen as a catalyst for more responsive health services that not only meet current health needs, but also attempt to re-address this balance.

#### 2.2 What evidence is there that CYP are participating in decision-making about individual healthcare?

It was clear that CYP wanted to make decisions about their personal healthcare (Cavet & Sloper 2004 a,b), however, the review process found little critical evaluative, published literature about how this occurred in practice across the various healthcare settings that CYP access. The review also highlighted that whilst there were many positive examples of individual CYP involved in consultations, rarely were they full partners (or fully participating) in terms of healthcare services. Instead, it was found that most communication and decision-making typically occurred through parent-provider interaction and/or adult health carers (Young *et al.* 2003; Coad & Shaw, 2006). This was especially the case for CYP who were 'ventilator dependent'; 'looked after' by the local authority; living in isolated, rural areas; 'hard to reach' groups; in residential schools or care and/or had communication difficulties (Noyes, 2000a/b; Cavet & Sloper, 2004b). The findings from Cavet & Sloper's (2004b) extensive review, in particular, highlighted the urgent need for internal and external evaluations of CYP's involvement.



We found many innovative examples of consultation with CYP. Examples drawn here include RCN Research Society Conference (March, 2006); RCN Research in Child Health Group (June, 2006); RCN *Making Children and Young People Matter* (September, 2006) and Childhood and Youth: Choice and Participation International Conference (University of Sheffield, July, 2006). (See *conference proceedings and speakers such as Gibson et al; Coad; Fletcher; Moules; Bell; Coyne; Heaton & Sloper; Sutcliffe et al; Wills et al; Lambert et al; Carter; Hewlett & Mee and Simon*). Despite this, there is not as yet a substantial body of evidence that clearly demonstrates that CYP are both involved and having impact on their own healthcare or health services (Bekker *et al.* 1999; Tates & Meeuwesen 2001; Kirby & Bryson, 2002; Lightfoot & Sloper 2003; Hunt, 2004).

Interestingly, the scoping exercise also revealed little published evidence about the extent to which CYP wanted to participate in decision-making processes. Nor has there been any clear indication about what they would prefer to make decisions on, for example; which specific aspects of their individual care. This said, various authors have highlighted that participation in decision-making may improve treatment adherence amongst adolescents with chronic illness (Kyngas *et al* 2000; Cavet & Sloper, 2004). Ways in which CYP could be and in some cases are being involved in healthcare services are drawn from O'Malley (2004) in Table 1, but will be discussed further in Section 4 of the review.

**Table 1. Ways in which CYP can be involved in decision-making**

<ul style="list-style-type: none"> <li><input type="checkbox"/> Research, analysis and policy development</li> <li><input type="checkbox"/> Project design such as involvement in managing projects or institutions</li> <li><input type="checkbox"/> Peer representation, participating in conferences, advocacy, campaigning, lobbying, publicity and media work</li> <li><input type="checkbox"/> Consultation exercises</li> <li><input type="checkbox"/> Monitoring decisions, auditing and evaluating services</li> </ul>
(Adapted from O'Malley, 2004)

### 2.3 What are the benefits of CYP participating in decision-making?

Almost all of the documents accessed provided a rationale for why CYP should be involved in making decisions about services. Further, the value of participation of CYP in public decision-making is now well accepted, and is recognised in the standards set in the National Service Framework (DH, 2003). At one level, participation was felt to embody important principles of citizenship; as highlighted in Section 1, it is a manifestation of children's rights enshrined in the UNCRC. It was thus thought to strengthen future democracy by engaging CYP in the democratic process and preparing them for their civil rights and responsibilities in adulthood. In addition, outcomes have included citizenship and social inclusion of young people, improved relationships between adults and young people, personal development for the young people involved, increased confidence and self-esteem, empowerment, communication skills, group work and practical skills (Kirby *et al.*, 2003).



One example of where participation has been thoroughly influential, is within Save The Children who recognised that CYP provide a different view (O'Malley, 2004). Consequently, researching their experiences and viewpoints is key to the work they carry out. In addition to Save the Children, however, the literature has shown that, despite a dearth of evaluation, there are many organisations that feel that involving CYP, can aid planning, make provision more appropriate and help introduce change (Kirby & Bryson, 2002). At a more pragmatic level, the literature has highlighted CYP's participation leading to services that are more responsive to CYP's actual needs and wishes, rather than those attributed to them by others. For example, Franklin & Sloper (2004) experienced that children and young people's views or wishes were not necessarily complex, unrealistic or hard to achieve, and that with the right resources, skills and time, most children, even those with 'complex communication disorders or severe learning disabilities, could be involved'. Thus, as Franklin & Sloper (2004) conclude, the value of children's views and insight should not be underestimated as, by enabling better use of resources, they can enhance services in practical ways

In addition, to the practical outcomes of developing CYP's participation, the literature review identified that involvement can also be a means of personal development (Kirby & Bryson, 2002; Hallstron & Elander, 2004). Hallstron & Elander (2004) in their study using observation methods, aimed to explore how CYP were involved in the decision-making process during hospitalisation. They found that CYP and their parents made few decisions themselves and even if they disagreed with the decision made, few were re-considered. They concluded that having a voice in decision-making would have helped the CYP to develop a sense of themselves as a person and given parents a feeling that they are part of a team (Hallstron & Elander, 2004).

The CYP themselves certainly expressed a desire to participate in the development and review of health services, and valued the chance to make a difference (Gibson *et al*, 2006; Coyne, 2006; Lightfoot & Sloper 2002). They stated that in being asked to participate they felt valued and respected. In addition to placing intrinsic value on these, the CYP have also highlighted benefits, which include enhanced confidence, self-esteem, skills-development, having fun and meeting new people (Lightfoot & Sloper 2002, Kirby & Bryson, 2002). Table 2 illustrates some of the benefits for the CYP, parents and/or carers drawn from key pieces of the literature. Benefits for the organisations undertaking CYP's participation are included in the following section.



**Table 2 Benefits of incorporating Children and Young People's participation in the development of individual care and service development**

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

- ☐ Ensures that research does not just measure outcomes that are identified as important by professionals.
- ☐ They can help to ensure that the issues that are identified and prioritised are important/relevant to them and therefore to healthcare as a whole (Steel, 2004).
- ☐ It can aid personal development with young researchers gaining knowledge, skills and confidence (Kirby, 1999; Wright *et al*, 2005) particularly amongst those who are often excluded ([www.healthpromotingschools.co.uk](http://www.healthpromotingschools.co.uk)).
- ☐ Emotional well-being, promoted through the development of social networks and life choices (Kirby, 1999) and provides the opportunity to influence decisions that affect their lives (Wright *et al*, 2005).
- ☐ Enjoyment (Wright *et al*, 2005).
- ☐ Opportunity to develop social networks, feel valued and empowered (Wright *et al*, 2005).
- ☐ Challenge negative images and stereotypes concerning mental health issues (Kirby, 1999).
- ☐ Empowers them to be creators of services, projects and activities – not just recipients of them and enables them to share experiences so as to learn from each other (Kirby, 1999).
- ☐ Increases CYPs knowledge and access to decision-making structures (Kirby, 1999; Wright *et al*, 2005).

### **Parents, Carers and Families**

- ☐ Empowerment
- ☐ Inclusion
- ☐ Improved health
- ☐ Improved achievement
- ☐ Improved communication
- ☐ Improved relationships
- ☐ Support with projects and activities
- ☐ Stronger community links

## 2.4 What are the barriers to CYP participating in decision-making?

There are several issues pertaining to why individual CYP's participation may be problematic. Firstly, the factors associated with decision-making, regardless of age, are likely to depend upon the context of the decision, the decision-makers and the ways in which the decision is framed and supported (Bekker *et al.* 1999). However, little is known about how these many factors influence the decision-making of CYP, or their parents. As such, we found little firm evidence about how best to support CYP in participating in their healthcare. Key examples that were identified were drawn upon in Section 4.

Studies on CYP's participation have shown that when their views are ignored by adults, this can decrease their self-esteem and stop them getting involved again. Indeed, Kirby (2002) noted that participation could have a negative effect if CYP's expectations are raised unrealistically and they later find out that their views have been ignored. Thus a consultation can co-opt CYP into a time-consuming process and waste their energy & enthusiasm. However, according to a variety of other authors, none of these cautions should be taken as a case for advising against involving CYP's participation in decision-making processes (O'Malley, 2004; Cavet & Sloper, 2004). Instead, they are intended to prompt discussion about better ways to ensure that participation in health and social care organisations empower CYP.

It may be the case that CYP prefer a collaborative role. Research with adults show that most prefer this method, to one that places them either as a passive recipient of care, or in total control (Doherty & Doherty, 2005) and this is probably also true for CYP. In part, Hill *et al* (2004) note that the failure to support the full participation of individual CYP, can be attributed to adult self-interest. As Hill *et al* (2004) note, there *"is a view of children's rights as undermining adults' authority and rights, with a zero-sum assumption that transferring responsibility to children inevitably takes something away from adults"*. A criticism often levelled at research with CYP is that both the agenda and process are controlled by adults with little consideration of their salience to those involved. The review of the literature supports this, with few of the projects appearing to be shaped by CYP. (See also Section 3.4).

## 2.5 How can we overcome the individual challenges?

Individual CYP's participation is thus only at a fledgling stage with most participatory initiatives being centred on consultations to gather views and experiences. This is clearly a huge step forward, but it does not involve CYP taking the lead in decision-making around the advocacy process. Nevertheless, these consultative initiatives are a good start, and have broken new ground in recognising CYP's experiences and their ability to provide valuable insights to inform policy-making issues that affect them (O'Malley, 2004; Brooks, 2006; Gibson *et al*, 2006;).



In order to overcome the identified challenges several authors have recommended the supporting role of advocates for CYP (Cavet & Sloper 2004a). This ranges from professional adult advocates to relevant voluntary organisations and peer mentoring. Other authors suggest access to independent mediation services may also be useful when there are discrepancies between CYP, their parents and/or health-professionals. Moreover, as Kirby *et al* (2003) note “*accepting responsibility for someone does not mean taking responsibility away from them*”.

The literature also suggests a number of strategies derived from professional opinion and clinical practice (Larcher 2005; Dixon-Woods *et al.* 1999). A number of resources are also listed by organisations such as the DH and the DfES, ([www.dfes.gov.uk/integratedchildrenssystem/involvingchildren/involving1.shtml](http://www.dfes.gov.uk/integratedchildrenssystem/involvingchildren/involving1.shtml)) and Children’s Rights Alliance for England ([www.crae.org.uk](http://www.crae.org.uk)), with many more are available to purchase. Key examples are included as a useful resource in Table 3.

**Table 3**      *Useful Resources – Identifying appropriate approaches to consulting with children and young people*

<p>Kirby, P et al (2003) <b>Building a Culture of Participation</b>. DfES. Research Report – <a href="http://www.cypu.gov.uk/corporate/docs/5146-DfES-Buil1].Part-Main-COV.pdf">www.cypu.gov.uk/corporate/docs/5146-DfES-Buil1].Part-Main-COV.pdf</a> Handbook – <a href="http://www.cypu.gov.uk/corporate/docs/5147-DfES-BuildPart-H'book.pdf">www.cypu.gov.uk/corporate/docs/5147-DfES-BuildPart-H'book.pdf</a></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Study carried out by the National Children's Bureau (NCB) and the PK Research Consultancy, which examine participatory practice with children and young people through case studies of 29 organisations.</li> <li><input type="checkbox"/> It concludes that meaningful participation is about developing positive relationships with children and young people, in which they are listened to and heard as part of everyday practice.</li> <li><input type="checkbox"/> The handbook, designed for management and staff at different levels within an organisation, aims to stimulate thinking, offer ideas about how to actively involve children and young people in decision-making, and to encourage organisations to explore how they can develop a more participatory culture.</li> </ul>
<p>Shepherd, C and Treseder, P (2002) <b>Participation – spice it up!</b> Save the Children. London</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> A Swansea-based cooperative using participative methods with children and young people, this manual provides practical tools for engaging children and young people in planning and consultations.</li> <li><input type="checkbox"/> It is based on activities used with children and young people from 18 months to 25 years in a range of settings, including play leader training, whole school policy making and consultations.</li> <li><input type="checkbox"/> Explores issues such as bullying behaviour and discipline and tackling problems of young people who feel excluded.</li> </ul>
<p>Treseder, P (1997) <b>Empowering Children and Young People</b>. Save the Children</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Manual of checklists and exercises, aimed at professionals promoting children and young people's empowerment in a range of sectors.</li> <li><input type="checkbox"/> Section 1 focuses on helping professionals to increase their understanding of issues relating to empowering young people in their work, while</li> <li><input type="checkbox"/> Section 2 focuses on training young people to be active in decision-making by building their confidence and skills. The final part looks at long-term strategies for making empowerment work.</li> </ul>



## Useful resources – Identifying appropriate approaches to consulting with children and young people continued

<p>Cohen, J and Emanuel, J (1998) <b>Positive participation involving young people in health-related work: a planning and training resource</b>. Health Education Authority (now Health Development Agency)</p> <p><a href="http://www.hda-online.org.uk/documents/positiveparticipation.pdf">www.hda-online.org.uk/documents/positiveparticipation.pdf</a></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Practical guide covering getting started, key practice issues, and strengths and weaknesses of different methods.</li> <li><input type="checkbox"/> Also outlines different activities which can be used for planning, learning and training purposes.</li> </ul>
<p>Combe, V (2002) <b>Up for it: Getting young people involved in local government</b>. The National Youth Agency.</p> <p><a href="http://www.jrf.org.uk/knowledge/findings/government/632.asp">www.jrf.org.uk/knowledge/findings/government/632.asp</a></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Report of research project focusing on young people aged 10 to 25.</li> </ul>
<p>Mumby, C (2001) <b>Building User Involvement: a step by step guide to involving users in youth information advice, counselling and support services</b>. Youth Access.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Offers detailed guidance, including examination of the uses of different approaches and their advantages and disadvantages.</li> <li><input type="checkbox"/> Approaches considered include questionnaires, computers, interviews, focus groups, peer research, participatory evaluation and committees and planning groups.</li> <li><input type="checkbox"/> Also identifies constraints and difficulties, formal structures underpinning involvement, and provides case studies of examples of involvement.</li> </ul>
<p><b>Participation Works! 21 techniques of community participation for the 21st Century</b> (2000)</p> <p><a href="http://www.neweconomics.org/gen/uploads/doc1910200062310PWA4.doc">www.neweconomics.org/gen/uploads/doc1910200062310PWA4.doc</a></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Handbook on techniques for community participation.</li> <li><input type="checkbox"/> Each entry contains a definition and description, details of resources needed, and a case study.</li> <li><input type="checkbox"/> Techniques covered include citizens' juries, future search, guided visualisation, participatory appraisal, forum theatre and planning for real.</li> <li><input type="checkbox"/> It also gives advice on how to choose the most appropriate technique.</li> </ul>
<p><b>Partnership Online</b></p> <p><a href="http://www.partnerships.org.uk/guide/AZpartic.html">www.partnerships.org.uk/guide/AZpartic.html</a></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Range of information on partnership and participation (but with no specific focus on young people) including A-Z of effective participation at website.</li> </ul>
<p>Aylward, N., Jackson, C. and Merton, B (2002) <b>The Learning and Skills Council Guide to Engaging with Young People: putting learners in the driving seat</b>. The National Youth Agency for Learning and Skills Council.</p> <p><a href="http://www.lsc.gov.uk/news_docs/Engage_YoungPeople.pdf">www.lsc.gov.uk/news_docs/Engage_YoungPeople.pdf</a></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Information and advice about good practice in consulting with young people aged 14 to 19, both the engaged and hard-to-reach groups.</li> <li><input type="checkbox"/> It outlines key issues, including who to consult, what to consult about, how to consult, what to do with the findings, recognition and awards and sustaining engagement.</li> </ul>

## ***Useful resources – Identifying appropriate approaches to consulting with children and young people continued***

<p>Fajerman, L (2001) <b>Children are service users too: a guide for consulting children and young people.</b> Save the Children.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Practical guide for organisations seeking to draw up a strategy for consulting children and young people.</li> <li><input type="checkbox"/> It includes checklists to help guide those who are less familiar with consulting children and young people through the process and provides a set of activities differentiated by age, for use with children from 2 upwards.</li> </ul>
<p>Fajerman, L., Jarrett, M and Sutton, E (2000) <b>Children as Partners in Planning: A training resource to support consultation with children.</b> Save the Children.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Intended for all childcare workers and professionals associated with Early Years Development and Childcare Partnerships who are working to fulfil DfES guidance on consulting with children on local childcare plans.</li> <li><input type="checkbox"/> It includes an explanation of what consulting children involves, three training programmes with photocopyable resources and handouts, case studies, and activities to use with children.</li> </ul>
<p>Madden, S (2001) <b>Re-action consultation toolkit: a practical toolkit for consulting with children and young people on policy issue.</b> Save the Children Scotland Programme.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Produced as part of Scottish Executive's Action Programme for Youth, this practical guide is organised in ten main sections.</li> <li><input type="checkbox"/> They cover: why consult, the principles of participation, ways of including people, planning and preparing for a consultation, the main approaches and methods of consulting, techniques and tools, methods of recording, transferring ideas and information, and suggestions for good practice.</li> </ul>
<p>Morris, J (1998) <b>Don't Leave Us Out: involving disabled children and young people with communication impairments.</b></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Report research with young disabled people, which covers the practicalities such as gaining consent, planning visits, using facilitators and being with the young people.</li> </ul>



## Useful resources – Identifying appropriate approaches to consulting with children and young people continued

<p><b>Ask Us</b> (2001 and 2003) The Children's Society  <a href="http://www.jrf.org.uk/knowledge/findings/social-care/741.asp">www.jrf.org.uk/knowledge/findings/social-care/741.asp</a></p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> SCD-Rom resulting from a multi-media consultation in which over 200 disabled children and young people aged 4 to 24 from across England were involved.</li> <li><input type="checkbox"/> Addresses issues such as access to leisure, participation and social exclusion, communication and services.</li> <li><input type="checkbox"/> Particularly aimed at those responsible for implementing the Quality Protects Initiative, but relevant to decision-makers in all sectors.</li> <li><input type="checkbox"/> The CD-Rom also looks at the rights of young disabled people in inclusive services.</li> </ul>
<p>Miller, J (1996) <b>Never too young: how children can take responsibility and make decisions.</b> Save the Children/National Early Years Network.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Practical resource showing how children under 8 years can participate, make decisions and take responsibility for their actions.</li> <li><input type="checkbox"/> It provides early years workers with information about why participation works, and includes a range of tried and tested techniques for involving children in decisions that affect them.</li> <li><input type="checkbox"/> Explores issues such as bullying behaviour and discipline and tackling problems of young people who feel excluded.</li> </ul>
<p>Ward, L (1997) <b>Seen and Heard: Involving disabled children and young people in research and development projects.</b> YPS.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Report covering background issues, the context, the law, practicalities of involving children, ethical issues, and equal opportunity issues.</li> <li><input type="checkbox"/> There is a section on children with sensory, profound or multiple impairments, and a four page checklist for action summarising key issues.</li> </ul>
<p>Wade, H and Badham, B (2003) <b>Hear by Right: standards for the active involvement of young people.</b> The National Youth Agency/Local Government Association.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Hear by Right offers tried and tested standards for organisations across the statutory and voluntary sector to assess and improve practice and policy on the active involvement of children and young people.</li> <li><input type="checkbox"/> The standards cover seven areas: shared values; strategy; structure; systems; staff and elected members and trustees; skills and knowledge, and style of leadership, forming a model of how to achieve change in an organisation.</li> </ul>

## *Useful resources – Identifying appropriate approaches to consulting with children and young people continued*

<b>Article 12</b> <a href="http://www.article12.com">www.article12.com</a>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Organisations run by and for children and young people under 18, campaigning on children's rights.</li> </ul>
<b>British Youth Council</b> <a href="http://www.byc.org.uk">www.byc.org.uk</a>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Independent charity and coalition of 150 organisations, run for and by young people, in order to represent their views to government, the media and others.</li> <li><input type="checkbox"/> It organises and facilitates consultations with young people, supports local youth councils, and runs a participation training programme for young people and practitioners.</li> </ul>
<b>Carnegie Young People Initiative</b> <a href="http://www.carnegie-youth.org.uk/html/publications-test.htm">www.carnegie-youth.org.uk/html/publications-test.htm</a>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Promotes the involvement of young people aged 10-25 in public decision-making.</li> <li><input type="checkbox"/> Its 'Taking the Initiative' series of reports maps activity to promote young people's involvement in public decision-making in the fields of national and local government, education and health in the UK and Ireland, and overseas.</li> </ul>
<b>Children's Rights Alliance for England</b> <a href="http://www.crights.org.uk">www.crights.org.uk</a>	<ul style="list-style-type: none"> <li><input type="checkbox"/> An alliance of over 180 organisations committed to children's human rights through the fullest implementation of the UN Convention on the Rights of the Child.</li> </ul>
<b>The Children's Society</b> <a href="http://www.childrenssociety.org.uk">www.childrenssociety.org.uk</a>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Works with marginalised children and young people, focusing on tackling the root causes of the problems they face.</li> </ul>
<b>Department for Education and Skills (DfES)</b> <a href="http://www.dfes.gov.uk">www.dfes.gov.uk</a>	<ul style="list-style-type: none"> <li><input type="checkbox"/> The Participation Team and the Children, Young People and Families Directorate is responsible for supporting cross-government work on children and young people up to 19, and promoting active dialogue and partnership with children and young people.</li> </ul>
<b>Groundwork</b> <a href="http://www.groundwork.org.uk">www.groundwork.org.uk</a>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Aims to build sustainable communities through partnerships in deprived areas throughout the country. Its youth programme aims to help young people play a full and active part in their communities, and has a focus on participation and empowerment.</li> <li><input type="checkbox"/> Specific initiatives include Youth Works and Young Voices (with Save the Children)</li> </ul>



## Useful resources – Identifying appropriate approaches to consulting with children and young people continued

<p><b>National Children's Bureau</b> www.ncb.org.uk</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Aims to promote the interests and wellbeing of all children and young people across every aspect of their lives.</li> <li><input type="checkbox"/> Promoting participation and young citizenship is a major theme of its work.</li> </ul>
<p><b>Save the Children</b> www.scfuk.org.uk</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> International children's charity with focus on children's rights.</li> </ul>
<p>Cutler, D &amp; Taylor, A (2004) <b>Expanding and sustaining involvement – a snapshot of participative infrastructure for young people living in England.</b> Carnegie Young People Initiative. www.dfes.gov.uk/research/data/uploadfiles/Expandingandsustaining.pdf</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Examines participation infrastructure – i.e. systems and procedures, structures and resources – in the voluntary and statutory sectors in England. Eight key aspects were identified: policy; budgets; champions; structures; specialist staff; training; guidance and monitoring.</li> </ul>
<p>Kirby, P. (1999) <b>Involving Young Researchers: how to enable young people to design and conduct research.</b> York: York Publishing Services.</p>	
<p>Laws, S., with Harper, C. and Marcus, R. (2002) <b>Research for Development: A Practical Guide.</b> London: Sage and Save the Children</p>	
<p>Warrall, S. (2000) <b>Young People as Researchers: A Learning Resource Pack.</b> London: Save the Children Fund</p>	
<p>Willow, C (2002) <b>Participation in Practice: Children and young people as partners in change.</b> The Children's Society. www.childrenssociety.org</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Book includes detailed examination of policy context for consultation and participation with children and young people.</li> <li><input type="checkbox"/> Explores four independent themes: the case for involving children and young people in decision-making; why children and young people are excluded; how adults can respect children and young people and acting on children and young people's ideas and views.</li> <li><input type="checkbox"/> Six case studies reflect the different models and approaches used by The Children's Society, including a school inclusion project, advocacy in the child protection system, using festivals to consult young carers, Ask Us project with young disabled people (see below), listening to very young children, and setting up a children and young people's bureau.</li> </ul>

## *Useful resources – Identifying appropriate approaches to consulting with children and young people continued*

Browning, S (2003) <b>Engaging Young People in Evaluation and Consultation</b> . New Opportunities Fund.	Review of issues and best practice in engaging young people in evaluation.
Campbell, R and Berry, H (2001) <b>Action Research Toolkit</b> . Edinburgh Youth Social Inclusion Partnership.	<ul style="list-style-type: none"> <li><input type="checkbox"/> Toolkit produced to help workers and organisations using action research – a developmental process with workers and young people jointly contributing to resolving issues and concerns.</li> <li><input type="checkbox"/> It outlines basic principles of action research, with good practice tips and practical tools to support exploratory work with young people.</li> </ul>
Clark, A and Moss, P (2001) <b>Listening to Young Children – The Mosaic Approach</b> . National Children's Bureau.	<ul style="list-style-type: none"> <li><input type="checkbox"/> Looks at how young children's views and experiences can become the focus for reviewing services.</li> <li><input type="checkbox"/> The Mosaic Approach is a Multi-method approach in which children's own photographs, tours and maps can be joined to talking and observing to gain a deeper understanding of children's perspectives on their early childhood setting.</li> </ul>
France, A (2000) <b>Youth researching youth: The Triumph and Success peer research project</b> . The National Youth Agency. <a href="http://www.jrf.org.uk/knowledge/findings/socialpolicy/d30.asp">www.jrf.org.uk/knowledge/findings/socialpolicy/d30.asp</a> .	<ul style="list-style-type: none"> <li><input type="checkbox"/> Evaluation of two-year peer research project in which 8 young people aged between 15 and 21 undertook research on youth transitions in Sheffield.</li> </ul>
Michel, E and Hart, D (2002) <b>Involving young people in the recruitment of staff, volunteers and mentors</b> . National Children's Bureau.	<ul style="list-style-type: none"> <li><input type="checkbox"/> Training pack includes information to help organisations develop policy procedures and structures, and training materials for a two-day accredited course to give young people the skills to participate effectively.</li> </ul>



<b>Web-based – Useful resources – Identifying appropriate approaches to consulting with children and young people continued</b>	
<a href="http://www.crae.org.uk">www.crae.org.uk</a>	<input type="checkbox"/> Useful easy to read 'Ready Steady Change' packs.
<a href="http://www.ne-cf.org">www.ne-cf.org</a>	<input type="checkbox"/> National Evaluation of The Children's Fund (Evaluators Cookbook).
<a href="http://www.childrenfirst.nhs.org">www.childrenfirst.nhs.org</a>	<input type="checkbox"/> 4,000 pages of relevant child health information with age related sites.
<b>Joseph Rowntree Foundation</b> <a href="http://www.jrf.org.uk">www.jrf.org.uk</a>	<input type="checkbox"/> National Charity committed to research into inequalities and CYP.
<b>National Youth Agency</b> <a href="http://www.nya.org.uk">www.nya.org.uk</a>	<input type="checkbox"/> Most recent consultation web site developed by the National Youth Agency. Excellent links to tool kits and key references relating to participation.
<b>Young Minds</b> <a href="http://www.youngminds.org.uk">www.youngminds.org.uk</a>	<input type="checkbox"/> National charity committed to improving the mental health of CYP. Provides guidance about putting participation into practice.
<a href="http://www.invo.org.uk">www.invo.org.uk</a>	<input type="checkbox"/> National Advisory Group supporting public involvement in NHS, public health and social care research.
<a href="http://www.nhs.uk/youngpeople">www.nhs.uk/youngpeople</a>	<input type="checkbox"/> NHS gateway to websites developed specifically for CYP covering a wide range of health and care issues.
<a href="http://www.childrenscommissioner.org">www.childrenscommissioner.org</a>	<input type="checkbox"/> Commissioner for England website.
<a href="http://www.cypcommissioner.org">www.cypcommissioner.org</a>	<input type="checkbox"/> Scotland commissioner website. All languages accessible including British sign language.
<a href="http://www.children.org.uk">www.children.org.uk</a>	<input type="checkbox"/> Well developed Welsh commissioner website.
<a href="http://www.niccy.org">www.niccy.org</a>	<input type="checkbox"/> Northern Ireland website with useful information for younger children.

### COLLECTIVE ISSUES (MACRO) OF CYP's DECISION-MAKING IN HEALTHCARE

#### 3.1 Background

As highlighted, much has been written in support of increased participation and decision-making for CYP in terms of their influence on health and social care policy. Collective issues outlined here were drawn from academic papers and reports produced by professional bodies, charitable foundations, patient/consumer organisations and independent think-tanks. The quality of the evidence base varied between reports and only a few were specific to CYP's healthcare services. Further, it is only recently that consultation events with CYP in terms of healthcare service planning and delivery have taken place. Conversely, recommendations were generally consistent and provided good direction for those committed to involving CYP in the development of health service policy and practice.

Most of the literature suggested that the level of involvement should be based upon the circumstances of individual service initiatives and include the preferences of the CYP as a group. Further, what is agreed 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 (Aynsley-Green et al, 2000; NSF, 2004). The review found several practical guides and accepted principles to involving CYP and participation (Gallagher, 2005; Kirby 1999; Lets Get Involved, 2003; NE-CF 2005; Listen Up 2005; Ask us 2005; Hear by Right 2005; Action for Sick Children, 2000; 2006). All stress that CYP have different preferences for participation and therefore, suggest a range of different activities and methods, which are included in Table 4. (See also Coad & Shaw, 2006). A particular useful resource is the most recently published Action for Sick Children (2006) guide, which builds on their millennium charter and includes sound principles for involving CYP in the service planning and delivery processes for hospital services. In summary, there are a range of documents and initiatives, which advocate a range of relevant participatory activities and methods for CYP. In terms of published literature, the reality and evaluation of using these in healthcare with CYP to date is limited.



**Table 4: Participatory activities and methods (Adapted from Coad & Shaw, 2006)**

TYPES OF PARTICIPATORY ACTIVITY (AND METHODS)
<p><b>Regular involvement activities of CYP</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Management committees</li> <li><input type="checkbox"/> Youth forums and councils (advisory and/or active roles)</li> <li><input type="checkbox"/> Commissioning and strategy groups</li> <li><input type="checkbox"/> Lobbying and campaigning groups</li> </ul>
<p><b>Time-limited activities of CYP</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Project advisory/steering groups</li> <li><input type="checkbox"/> Involvement in research activities (as researcher and/or participant) using: <ul style="list-style-type: none"> <li><input type="checkbox"/> <i>Survey/questionnaires</i></li> <li><input type="checkbox"/> <i>Face-to-face interviews</i></li> <li><input type="checkbox"/> <i>Focus groups/discussion groups</i></li> <li><input type="checkbox"/> <i>Consensus methods (delphi/nominal group methods)</i></li> <li><input type="checkbox"/> <i>Mapping activities</i></li> <li><input type="checkbox"/> <i>Activity based methods (Drama/role play)</i></li> <li><input type="checkbox"/> <i>Arts based methods (Draw and write/photography/video-making)</i></li> </ul> </li> <li><input type="checkbox"/> Attendance at meetings/conferences</li> </ul>
<p><b>Service-delivery activities of CYP</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Peer educators</li> <li><input type="checkbox"/> Peer counselling</li> <li><input type="checkbox"/> Peer mentoring</li> <li><input type="checkbox"/> Peer befriending</li> <li><input type="checkbox"/> Training and examination of professionals</li> <li><input type="checkbox"/> Organising and presenting at conferences</li> </ul>
<p><b>Indefinite activities of CYP</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Suggestion boxes</li> <li><input type="checkbox"/> Email/internet (feedback, discussion, polls etc)</li> </ul>

### 3.2 What evidence is there that CYP are participating in having collective choices about healthcare services?

CYP's collective choice about service provision was predominantly discussed in relation to their "participation" or "involvement" in the decision-making process. In the context of health, much of the work has been confined to health promotion issues with less involvement reported on the acute, chronic, community and transition services for CYP (NSF, 2004). Two years on from the NSF (2004) it is anticipated that this is set to change. The review also identified a number of published articles and documents that described the involvement of CYP in health service development, which further supported the belief that CYP are able to give their views, given the opportunity.

As evidenced in Section 3.2.1, the review explored in depth hospital-based services (including inpatient, outpatient and transitional care) and community services (primary care, CAMHS, sexual health clinics, respite care and home care). Areas of investigation also included CYP's views regarding the patient-provider relationship, service environment and process issues. Taken together, these studies suggest that the quality of the relationship with healthcare professionals is the most important aspect of care for CYP and is evidenced through good communication skills and respect. Other important provider characteristics included medical and technical competence and friendliness. Whilst process issues were less important, CYP certainly valued continuity in care, confidentiality and support during transition. Where the built-environment was explored, CYP stressed the importance of age-appropriate facilities, privacy and access that acknowledged their existing commitments (e.g. school).

Evaluation is an important form of determining that giving CYP choice is improving healthcare service planning and delivery. Wright *et al* (2005) undertook a follow up study 'one year on' to evaluate how organisations who had involved CYP were following through on those consultations. In the case studies identified by Wright *et al* (2005), staff described their current participation practice as inclusive, however when asked to describe the profile of the CYP involved in the consultation, most of the samples were of white, able-bodied young adults. Little evidence was found of what had changed or improved in the organisation following the consultation. Thus, Wright *et al* (2005) concluded that policy, research and practice seemed to be at different stages and that an organisational cultural change about CYP's involvement was difficult to sustain.

Positive general examples were also drawn upon. One of these examples was the Children and Young People's Strategic Partnership in Swindon. This initiative specifically seeks to identify priorities for health and social service planning and development. All statutory, community and voluntary organisations working with CYP, Children's Champions and Non Executive Board members of local healthcare trusts are automatically members of the CYP's Strategic Partnership. The CYP are represented through existing participation initiatives, which are co-ordinated by the Young People's Involvement Forum, whose aims include:

- ☐ Listening to and taking account of views of CYP and parents
- ☐ Establishing integrated and co-ordinated services taking account of government policy; establishing a vision of Children's Centres
- ☐ Defining models of integrated and co-ordinated services
- ☐ Monitoring plans toward specific targets relating to national policy and guidance

The Children and Young People's Strategic Partnership in Swindon envisaged that CYP would receive benefits, similar to those highlighted by Kirby (1999), where services were co-ordinated, integrated and where CYP's social, educational, health and emotional potential would be maximised. However, evaluation was not yet evident from The Children and Young People's Strategic Partnership, Swindon to fully comment on the impact.



Further, Boylan (2004) in Children's Voices Project (CHI) undertook a postal questionnaire developed to capture the views of 104 national and locally based voluntary organisations which worked solely with CYP and health issues. Each organisation was asked to provide information about work they had carried out to gain feedback from CYP around particular health issues. Analysis of the areas of care included for example, by subject coverage: inpatient services, mental health, communication, environment, level of involvement, looked after children, adolescent services, general healthcare, information, advocacy and transition into adult services. Findings showed that despite there being little in terms of ongoing review of the initiatives reported, CYP can have very positive ideas about how these organisations could work better within these areas.

Wright *et al*, (2005) noted that participation in decision-making is a right of all CYP no matter how great the challenge for practitioners to involve them. However, Oldfield and Fowlers (2004) mapping of participation initiatives found significant disparities between the levels of involvement granted to different groups of CYP. In Oldfield & Fowlers (2004) work respondents reported some success in involving what are often seen as 'hard to reach' groups of CYP. However, two thirds of statutory agencies and half of voluntary agencies found it difficult to include the specific groups of BME, young people, those in rural areas, disabled children, and those who do not access education, training or employment.

Using largely published literature (or in press) it was felt useful to descriptively outline some **examples** of specific groups of CYP's involvement in healthcare services to determine inclusiveness. Examples are also drawn upon in Table 6, Table 12 and Section 4.

### **3.2.1 Inpatient**

Most of the studies used multiple methods including interviews (one to one and focus groups) and questionnaires with CYP. Samples were drawn from CYP who had been recently discharged (Carney *et al*. 2003; Battrick & Glasper, 2004; Coyne, 2006) or in hospital or were regular attendees of hospital at the time of the study (L4A 1990; Darbyshire 1994; Needham, 1997; Turner 2003; Coyne 2006; Coad *et al*, 2006). Several projects aimed to find out what facilities CYP would prefer (L4A 1990; Anshen Dyer 1999; Sharma & Finlay, 2003; Coad *et al*, 2006). One interesting study was the Coad *et al* (2006) study, which 'trained' a group of CYP to help collect data and verify analysis in a hospital-based research project.

Alison and Moules (2004) undertook a study in primary and secondary schools asking children aged 9-14 years about what they would like in terms of care in hospital. Moules (2002) also explored the case for involving CYP in clinical audit. Many studies were based across large, city areas and we found little work that referred to the specific issues of the rural CYP and in-patient services. An interesting study of 63 CYP's (aged 2–15 years) views of nursing and medical roles, using drawing and writing sheets during pre-admission events, revealed interesting information about views about healthcare personnel and the need for careful explanations (McDonald & Rushforth 2006).



### **3.2.2 Transitional Care**

Rabiee *et al* (2001) and Shaw *et al* (2004 a;b; McDonagh *et al*, 2006) have undertaken a series of qualitative interviews highlighting the issues of transitional care (child to adult services). Shaw *et al* (2006) also draws on the involvement of CYP in developing a model for transitional care.

### **3.2.3 Community Care including Sexual Health**

Dixon-Woods (2002) used in-depth interviews across two general practices (one rural and one urban) to highlight the important dimensions for CYP in community care in terms of services for those with childhood asthma. McNeish (2001) used an innovative approach, which involved young people in teenage pregnancy work. Conversely, Jacobson *et al* (2001) Linnell, (2002) and Nwokolo (2002) whilst drawing out interesting findings about community issues, all used questionnaires and focus groups to elicit data.

### **3.2.4 Mental Health (Child and Adolescent Mental Health Services – CAMHS)**

Farnfield *et al* (1998); Save The Children (2000); Stephens (2002); Roose & John (2003); (Street *et al* (2005) and Dogra *et al* (2005) all used semi-structured interviews and qualitative methods to highlight that CYP wanted accessible CAMHS services that were visible to them in community settings and appropriate for the age group. Interestingly, Law (1998) used more creative methods including art, poetry and drama to engage CYP. Street & Svanberg (2003); Street *et al* (2005) and Kurtz *et al* (2005) all explored ways of involving users of in-patient CAMHS and found similar findings about exploring different and non-traditional routes for sharing information for this group. Street *et al* (2005) focused on young people from BME communities, who identified the crucial role played by the media, local community and faith groups. This explored the experiences of young people from a range of different ethnic groups in using mental health services and identified the barriers to accessing help. Street *et al* (2005) identified that many young people reached help only at a critical point in their difficulties. The recommendations include suggestions from young people and staff from across a wide range of different service providers about how to improve this situation. Consequently, a guide to good practice has been developed which describes the service elements known to be important in providing mental health services for young people. This was supported with 19 detailed case studies of different approaches to service provision that appear to be making an important contribution to addressing some of the problems and gaps in provision identified in the research (Street *et al*, 2005)

### **3.2.5 Respite Care**

There were limited studies found in this area with regards to involvement of CYP in health-care services, which would indicate a need for further work. The most relevant, although over ten years old, was Minkes *et al* (1994) which used interviews to find that most CYP enjoyed respite care services but choice to attend was not always made and facilities were variable.



### **3.2.6 Black Minority Ethnic (BME)**

It is vital that CYP's voices from the most marginalised groups, such as those from Black Minority Ethnic groups (BME) are represented. Interestingly, research into the impact of Neighbourhood Fund and supporting the 'hardest-to-reach' young people (2004) found that organisations that succeeded in engaging with these CYP did so because they relied heavily on outreach work, establishing a positive reputation in the local community and linking with other agencies who had contact with specific groups of young people. However, the review highlighted very little work undertaken with CYP specifically in terms of their involvement in healthcare services. Williams (2004) purported that what is required is a framework for empowering BME marginalised groups, stating that a 'process of change through which those who have been denied the ability to articulate their needs, exercise those rights and influence the decision-making processes which shape their lives, are enabled to do so' is what is needed.

### **3.2.7 The Under Five Year Olds**

The review highlighted, that often the very young, or the under five year olds had been excluded from consultations or decision-making processes. Alternatively, parents and practitioners made decisions on their behalf. Oldfield and Fowler (2005) found that fewer than 20% of organisations that provided a service for under-fours involved them in decision-making, and only 54% said that they involved children aged five to eight. In addition to this Alderson (2000) provides examples of how babies as young as six months old are able to 'form and express a view' about their immediate surroundings, thus indicating that involving children as young as this, could be beneficial to organisations involved in their care.

### **3.2.8 Young People (searched also as adolescents)**

The review found many examples where young people aged 10 years and above had been consulted or were participants in the process. Coad & Needham (2005) used photographs to elicit the views of healthy young people about their life styles generally, but included views about health as a main focus to the work. Findings were validated with an 'expert' group of young people developed as part of the project. But in accessing young people there have been many identified barriers as outlined by McNeish (1999). (See Table 5).