A literature review on the participation of disabled children and young people in decision making

February 2013

Contents

List of figures

Acknowledgements

1.   Overview of the VIPER research project

Current policy encourages the involvement of children and young people in matters that affect them and evidence suggests that this has led to an increase in their participation in decisions relating to services over recent years. However, the participation of disabled children and young people has not increased correspondingly. There has been little research into the most effective ways of enabling disabled children and young people to participate in developing services, or into the ways they would like to be involved. In addition, organisations often lack the skills, knowledge and resources to bring about change.

This research, led by the National Children's Bureau Research Centre and in partnership with The Children's Society Research Unit, the Alliance for Inclusive Education and The Council for Disabled Children aims to provide the evidence to support the development of disabled children and young people's participation in England. It is a three and half year project funded by The Big Lottery Research grants programme (July 2010 until Spring 2014).

The project has a number of related components and benefits from the full involvement of 16 disabled young people who are advisors and co-researchers and have worked alongside the research team at all stages of the project. The first component of the research, reported here, is a review of existing research in order to establish what evidence is already available. A survey was then undertaken with organisations working with disabled children and young people to ascertain current practice. Following this, qualitative research in eight areas was undertaken, and detailed information was gathered to establish what works and why. In order to develop practice based on the evidence gathered, the findings of the research will be translated into practical resources which can be used by organisations and disabled young people. Further details on the research can be found in The VIPER project: how we did the qualitative research.

Specific project objectives were to:

- Investigate how services involve disabled young people in different types of decisions – decisions about long-term planning ('strategic' decisions) as well as decisions about the way things happen from day to day ('operational' decisions).

- Explore the impacts and benefits of disabled young people's participation.

- Understand the barriers to effectively involving disabled young people in decision-making.

- Seek out good practice and understand, from the viewpoints of services and disabled young people, what seems to work in supporting participation.

- Develop materials and resources with disabled young people to support their participation in decision-making.

A key element of the project was the participation of a group of disabled young people who have been trained and supported to become full members of the research team. Project partners were committed to developing and using innovative methods to support the disabled young researchers in playing a central role in the project, thus demonstrating to others the range of approaches that need to be embedded if participation opportunities are to be truly inclusive and relevant to disabled young people.

The young people created the name VIPER for the project to reflect what the research was about and what they wanted to achieve for other disabled young people. VIPER stands for Voice, Inclusion, Participation, Empowerment and Research. The young people now refer to themselves as *Vipers*. Because the literature review informed the development of the research it had to be undertaken at the beginning of the project. Due to time constraints, this coincided with when the Vipers were being recruited and trained. Therefore the literature review was undertaken by a researcher at The Children's Society. However Vipers used the literature review findings to inform the development of project and in particular to inform questions for the qualitative research phase. They have also used evidence from the literature review in the development of their policy and practice recommendations which can be found in Hear Us Out!

2. Aim and methodology of the literature review

This report provides an overview of available evidence concerning disabled children and young people's participation in strategic decision-making arenas. The review of evidence sought to examine:

- where participation is occurring/has occurred and subsequent gaps
- what processes are being used to facilitate disabled children's participation
- what appears to work well
- what barriers exist
- what is the impact and/or outcome of participation for this group of children.

The report includes an analysis of theory, policy, research and where possible, available practice and grey literature to create a picture of the participation of disabled children and young people in England.

To identify available evidence and reports the following search mechanisms were adopted:

- A search of relevant academic electronic databases including the Applied Social Sciences Index and Abstracts (ASSIA), Web of Knowledge and Child Data Abstracts (NCB's database).

- A search of relevant websites including government departments, and relevant national and voluntary organisations.

- Contact with key researchers known to be active in the field.

- A call for evidence circulated via contacts and relevant networks.

Inclusion criteria consisted of participation in all service areas of children's lives, articles published in English and published post 2000. (Some articles published prior to this date have been included where particularly relevant). No age parameters were set on the children participating.

The search terms consisted of words associated with participation and service provision; involvement, consultation, decision-making and evaluation and service provision such as education, health, social care, environment, transport and policy. The searches and call for evidence were undertaken at the beginning of 2011.

Every effort was made to ensure that this review presents an accurate picture of the available evidence of disabled children and young people's participation in strategic decision making in England. However, this report does not purport to be a systematic review of all evidence and therefore does have some limitations. For example, because of the limited evidence

available, none of the evidence has been systematically assessed for quality, although where pertinent any limitations are noted.

A thematic template was developed to analyse the data.

3. Theoretical background

This section describes the historical and current definitions, theories and debates concerning the participation of children and young people in decision-making.

Summary of the background to participation in decision-making

➢ The definition of participation is often contested and there is no one agreed definition.
➢ Children can participate in decisions that affect them as an individual and in decisions which relate to them as a group (collective or public decision-making).
➢ Participation is often described in terms of levels of power that are shared with children and young people.
➢ The level of power shared with children should be determined by circumstances and the wishes of the children taking part.
➢ Disabled children and young people are often denied opportunities to participate at even the lowest levels of decision-making because they are not given information and their access needs, such as communication needs, are not met.
➢ Participation has been increasing because of: children's rights and legal responsibilities, it leads to better services, promotes protection, citizenship and social inclusion.
➢ Research has shown that children are competent to make decisions, and that children previously considered incapable of participating can be involved if creative and flexible methods are used.
➢ Research has shown that disabled children sometimes have different views from their parents/carers and thus it is wrong to exclude them in favour of consulting their parents.
➢ Participation can lead to increased skills and confidence in children, and them taking increasing responsibility and control in their lives.

3.1 Definitions of participation

The term participation covers a broad continuum of involvement in decisions; it is a multi-layered concept, involving many different processes (Kirby et al, 2003a; Sinclair, 2004). While participation is commonly used to describe the process of listening to and engaging with children, the term is commonly contested (Lansdown, 2009). There is no one agreed definition. Boyden and Ennew (1997) state that participation can simply mean taking part, being present, being involved or consulted. Alternatively, it can denote a transfer of power so that participants' views have influence on decisions. Although the second definition is the prime concern of this research, the first is no less important or easy to achieve. Disabled children, for example, may lack the opportunity to participate in everyday activities, factors such as discrimination, unmet social and leisure needs, housing issues and inaccessible transport contributing to their social exclusion, as illustrated by, for example, Beresford (2002) and Morris (1998a, 2001a, 2001b).

3.2   Focus of participation activity

It is important when examining participation to distinguish the focus of children's participation as this can vary. Children and young people can influence decisions in matters that affect them as individuals, for example in reviews of their care, health or education. They can also influence decisions which relate to them as a group (collective or public decision-making), for example, the formation, review and/or implementation of policy, or the formation, delivery and/or evaluation of services, locally and nationally. Both decision making processes are important and not mutually exclusive, but the mechanisms to achieve involvement are likely to be different. As already specified, collective decision-making is the focus of the VIPER project.

A number of mapping exercises of collective decision-making have been undertaken (Cutler and Frost, 2001; Kirby et al, 2003a; Oldfield and Fowler, 2004; Davy, 2010) these identified a wide range of processes and activities being undertaken to facilitate participation. These include children and young people participating within research as respondents, advisers or as young researchers; as part of management committees, advisory groups, youth forums, community initiatives; or in delivering services by acting as mentors, counsellors, volunteers or workers (Sinclair and Franklin, 2000). All such activities were considered relevant for this review.

3.3   Typologies of participation

A number of writers have developed typologies to illustrate participation. These generally make distinctions between levels of participation according to the degree of power that is shared or transferred (Arnstein, 1969; Hart, 1992, 1997; Thoburn et al, 1995; Treseder, 1997). Shier (2001), for example, attempts to create a "pathway to participation" and encourages practitioners to explore the participation process, determine their current position and identify the next steps to be taken to increase the level of child participation. He identifies five levels of participation:

1) children are listened to
2) children are supported in expressing their views
3) children's views are taken into account
4) children are involved in decision-making processes
5) children share power and responsibility for decision-making.

Kirby et al offer a similar model to Shier although they choose to illustrate it in a less hierarchical form (See Figure 1).

Figure 1:   Kirby et al's model of the level of participation

	Children and young people's views are taken into account by adults	
Children and young people make autonomous decisions		Children and young people are involved in decision-making (together with adults)
	Children and young people share power and responsibility for decision-making with adults	

(Kirby et al, 2003a, p22)

Kirby et al (2003a) argue that the type of participation activity should be determined according to the circumstances and the participating children and young people. Likewise, Alderson (2002) argues that good practice should mean that practitioners ascertain from each individual the level of involvement that they desire, and continue to check this as wishes may change.

A simple framework by Alderson and Montgomery (1996) defines four levels at which children can participate:

1) being informed
2) expressing a view
3) influencing the decision-making process
4) being the main decider.

Taking Alderson and Montgomery's framework is a useful starting point for examining disabled children and young people's participation, evidence suggests that even level 1 and level 2 are often denied to disabled children and young people and therefore opportunities to reach the level of influencing decision-making are potentially limited. Franklin and Sloper (2009) argue that a preceding prerequisite should be considered whereby access to communication is also assured for those young people with communication needs. Thus guaranteed access to communication methods and access to people who understand a young person's communication method is the first stage in any participation activity. Linked to this is an understanding that communication takes many forms and is not just speech alone.

Although criticised models of participation help to distinguish between different levels of empowerment afforded to children and young people, highlight the need to understand the term participation and prompt examination of what kind of participation is appropriate. It is now generally accepted that the level of participation will vary depending on the objectives sought, the decision being made and the capability and choice of the children and young people. However, meaningful participation must be

seen as a process, not simply an isolated activity or event (Kirby et al 2003a).

3.4   Drivers towards increased participation

The acceptance of children and young people's participation and drive for increased participation has been influenced by a convergence of new and developing ideas coming from several different perspectives. McNeish and Newman (2002) identified five key areas of particular significance:

1) The growing influence of the consumer.

2) Pressure from young people's users groups – e.g. Young people-led organisations such as the British Youth Council and UK Youth Parliament have pushed for further opportunities to be heard.

3) The children's rights agenda and in particular the United Nations Convention on the Rights of the Child (UNCRC).

4) The 1989 Children Act and subsequent Inquiry Reports.

5) The growth of citizenship as a policy issue - McNeish and Newman (2002) argued that government commitment to a "stakeholder democracy" and the resurgence of interest in the concept of citizenship has contributed to a search for new ways of involving young people as "active citizens" within their communities and within local governance such as in the development of youth councils, youth parliaments and shadow boards.

In addition, many authors highlight the contribution made by the emergence of childhood studies and the increased understanding of the child as a competent social actor (see for example, James and Prout, 1990, 1997). There is also a growing understanding of the active role that children and young people can play in shaping the processes, structures and environment around them (James et al, 1998). Thus instead of being seen as recipients of services and passive objects of research, children and young people are seen as active participants or agents of change (see for example, Prendegast, 1992; Mayall, 1994; James et al, 1998). Closely allied to this is a changing understanding of, and attitude towards, the competence and capabilities of children, including young children, to be both commentators on their own lives and to be involved in decision-making (Alderson, 1993; Clark and Moss, 2001; Willow et al, 2004; Kirby et al, 2003a, 2003b). This has increasingly led to research placing children centre stage rather than relying on adults' perspectives, and to the development of more participatory methodologies to involve children and young people in research processes, and indeed undertake research themselves (see for example, Alderson, 2001; Kellett et al, 2010; Kellett, 2011). Disabled children have benefitted from this move away from "traditional" methods which were often inaccessible to them. Creative and flexible methodologies have enabled groups of children and young people previously deemed "incapable" or "hard to reach" to participate in research; for example, children with neuro-diversity, complex health needs,

communication needs and learning disabilities (see for example, Minkes et al, 1994; Stalker and Connors, 2003; Watson et al, 2006; Beresford et al, 2004, 2007; Rabiee et al, 2005; Lewis et al, 2005; Sloper et al 2009; Mitchell et al 2009; Greco at el, 2009; Mitchell, 2010; Mitchell and Sloper, 2010). Such research has illustrated that disabled children can express their views, have much to contribute, have differing perspectives to adults, and thus should participate in decision-making processes. The views of parents/carers had been, and in many cases still are, sought to the exclusion of disabled children and young people themselves. However, increasingly evidence is growing to support communicating with disabled children and young people directly and not treating their parents/carers as proxies. Research indicates that the two sometimes see things very differently (Franck and Callery, 2004). Stalker and Connors, for example, found that parents and their children had different views about a number of topics including what caused young people distress, how they behaved at school and what the future held for them (2003). Mitchell and Sloper (2001) identified that children and young people value different aspects of services than their parents.

3.5   Why participation is important

The case for children and young people's participation is well documented and is often grouped into legal, political and social reasons (Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; McNeish and Newman, 2002; Willow, 2002). Sinclair and Franklin (2000) summarise the reasons for involving children and young people in the following way:

> *"To uphold children's rights; to fulfil legal responsibilities; to improve services; to improve decision-making; to enhance democratic processes; to promote children's protection."*

In contrast, Matthews (2003) presents three alternative arguments based on education for citizenship, fitting young people into society and strengthening young people's status in relation to adults. The government themselves published three broad reasons for why children and young people should be involved: better services, promoting citizenship and social inclusion, and personal and social education and development (The Children and Young People's Unit, 2001). Willow (2002) argues that listening to and respecting children and young people can engage those previously deemed "in trouble" or marginalized, leading to enhanced relationships with adults and opportunities for participants to develop their social and communication skills and increase their knowledge and learning.

A number of writers have highlighted the benefits of participation for organisations and for young people themselves, although these observations are more likely to be based on anecdotal evidence than on systematic or rigorous evaluations (see for example, Treseder 1997; Cohen and Emanuel 1998; Hennessy 1999; Willow 2002; Badham and Wade 2005, 2010; Kirby et al 2003a; Willow et al, 2004). They state that participation enables resources to be targeted more effectively and improves quality of service provision. For children and young people, it is

argued that participation helps them to support and positively influence each other, increase empathy and responsibility, develop cognitive, communication and practical skills, provides opportunities to gain knowledge, understanding, experience, self-belief and confidence and encourages young people to take responsibility and control of their lives. Participation also increases young people's sense of ownership, belonging and commitment to services and enhances the skills of adults involved in planning and providing them. Although, Willow et al (2004) argue that the citing of these personal benefits of participation above other impacts reflects the fact that children and young people's views are often not seriously used in management decisions or in shaping policy.

Dickens (2004) argues that it is especially important for disabled children and young people to be consulted about the services they use and the support they receive, because this group is more often subject to assessments and medical interventions than other children. Priestley (2000) highlighted that many disabled children and young people are subject to increased surveillance in their lives leading to their disempowerment and increased adult control. As already established children and young people have differing opinions to parents/carers and place importance on different aspects of the support they receive or would like to receive. Indeed opportunities for making choices are deemed by disabled children and young people to be an important aspect of the quality of a service (Mitchell and Sloper, 2001).

When disabled young people themselves are asked why participation is important the continued messages that emerge are simple; *"I want more choice"*, *"Participation is a great way to help us learn how to make decisions and understand the choices we face in the future"* and *"You can find out what's best for us by involving us"* (quotes taken from the *Top Tips for Participation* poster produced by The Council for Disabled Children, 2008). Beresford (2002) cites research evidence which repeatedly shows that for disabled young people having their views respected and being involved in decision-making are highly valued features of service provision (for example, Morris, 1999a; Noyes, 1999; Crisp et al*,* 2000; Mitchell and Sloper, 2001). On a national level disabled young people prioritised participation within a manifesto for change which was produced in preparation for the last general election (Making Ourselves Heard and Every Disabled Child Matters Campaign, 2009).

However, Willow (2002) argues that focusing on the benefits of participation can sometimes obscure the fact that being listened to and taken seriously is a human right. Cutler and Frost (2001) had previously stated that:

> *"Participation should not be seen in purely utilitarian light – that young people will get better jobs or service providers will do their jobs better. It must be seen as a fundamental right as expressed in Article 12 of the UNCRC, and not something to be withdrawn if it fails to produce the right outputs."* (p6)

4.   Policy Context

This section illustrates how the participation of children and young people in decision-making in services has been defined, adopted and developed within policy in England.

4.1 The Children Act (1989) and Children Act (2004)

Although the United Nations Convention on the Rights of the Child (UNCRC) is often seen as the starting point and impetus for the development of participation; prior to this there were key requirements for children and young people's participation within the Children Act 1989 (Department of Health, 1991). This requires local authorities to ascertain the wishes and feelings of children they look after or are about to look after, and to give these due consideration, subject to practicability such as the child's age and understanding. For disabled children, guidance and regulations within the 1989 Children Act make it clear that, if a child has complex needs, communication needs or severe learning disabilities arrangements must be made to establish their views and that a disabled child cannot be assumed to be incapable of sharing in decision-making. The act requires local authorities to establish complaints procedures for children in need and looked after children. In addition, the 1990 NHS and Community Care Act (The Stationery Office, 1990) established a duty on the part of service providers to provide complaints procedures, and the 2002 Adoption and Children Act places a duty on local authorities to provide advocacy services to children who wish to make a complaint under the Children Act 1989 (The Stationery Office, 2002).

The Children Act 2004 (Her Majesty's Government, 2004) reinforces children's right to be listened to by service providers. Joint area reviews of education and social care and performance assessment of local councils examine the extent to which children and young people are listened to and their views taken seriously. This is applicable both within individual decision-making as well as wider service and policy development. The act also created statutory Lead Members for children's services and Directors of Children's Services (DCS). Statutory guidance on the role requires Lead Members to regularly consult children and young people and stresses the need for participation at a local level (DCSF, 2009). All authorities were required to produce an annual Children and Young People's Plan (CYPP), outlining their strategic plans for children and young people's services. It was a requirement that children, young people and parents/carers were consulted in the development of the plan[1]. During 2009, legislation established Children's Trust Boards in every local authority and these had the duty to produce CYPPs. Statutory guidance stressed the need for children to be consulted in the work of the board and for a children and

---

[1] Although it should be noted that disabled children and young people were rarely included in these plans (please see: Every Disabled Child Matters (2006) Off the radar: How local authority plans fail disabled children. Every Disabled Child Matters, London)

young people's version of the plan to be produced (DCSF, 2010). However, the coalition government withdrew statutory children's trust guidance in October 2010, and children and young people's plan regulations were revoked, thus Children's Trust Boards are no longer required to produce a children and young people's plan.

4.2 The United Nations Convention on the Rights of the Child (UNCRC) (1989)

The UNCRC adopted and ratified by the UK government in 1991 is often seen as creating the driver towards the increased participation of children and young people. Article 12 of the Convention states that:

> *"State parties shall 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."* (United Nations, 1989)

Article 13 is also pertinent to promoting children's and young people's effective participation, particularly disabled children and young people who may use a variety of communication methods. This article grants children the right to seek, receive and disseminate all kinds of information and ideas in a variety of forms. Willow (2002) states that this should serve to remind us that "*human communication takes many forms and is not confined to language alone*" (p32).
Article 13 states that:

> *"The child shall have the right to freedom of expression: this right shall include the freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice."* (United Nations, 1989)

The Convention applies to all children and young people from birth up to 18 years of age.

Other relevant legislation includes the Human Rights Act, 1998 (Article 10) which requires central and local government to uphold a right to freedom of expression and the Convention on the Rights of Persons with Disabilities (CRPD) (2006) which embodies the participation of disabled people, including children. In particular, Article 7 of the CRPD states that children with disabilities have the right to express their views freely on all matters affecting them, with their views being given due weight in accordance with their age and maturity on an equal basis with other children. In addition, they should be provided with disability and age appropriate assistance to realise that right.

4.3 Government initiatives, programmes and guidance

The following highlights a number of government initiatives over the last decade or so which have direct reference to the participation of children and young people in decisions about services.

Quality Protects (1999)

The importance of listening to children and young people has been reinforced by successive inquiries into the abuse of children, particularly within the looked after system (Utting 1997; Waterhouse, 2000; Laming, 2003). A recurring theme of these has been the failure of adults to listen to young people and the powerlessness of children and young people in local authority residential care. This concern led to an interest in more effective ways of empowering young people as a protective strategy, thus ensuring that children and young people have opportunities to make their concerns heard and that these concerns are taken seriously through avenues of the complaints procedure and access to independent advocacy. This notion was central to the government's Quality Protects initiative (1998) which aimed to transform both the management and delivery of social services for children and required mechanisms for children and young people's views to be heard (Department of Health, 1999a). Developing a culture of, and good practice in, children's participation was fundamental to achieving the overall aim of Quality Protects. However, ring fenced funding for Quality Protects ended in 2004 and practice was mainstreamed.

The Children's Fund (2001) and development of Children's Trusts (2003)

The participation of children, young people and parents continued to be at the centre of government policy and initiatives. For example, within the development of The Children's Fund (established in 2001), participation was one of the guiding principles of the initiative. Guidance stated that children, young people and parents should be actively involved in the design, delivery and evaluation of services (Children and Young People's Unit, 2001b). Likewise, within the development of Children's Trusts, listening to the views of children and young people was deemed fundamental to developing priorities at a strategic level, and trusts were required to gather evidence on how day-to-day practice affected them personally (Department for Education and Skills, 2003).

Aiming High for Young People (Ten Year Youth Strategy) (2007)

Children and young people's participation was at the heart of the ten year youth strategy which set out a series of commitments to transform opportunities for young people, including empowering them to have greater influence over the services they receive (HM Treasury and Department for Children, Schools and Families, 2007).

Aiming High for Disabled Children: Better Support for Families (2007)

Aiming High for Disabled Children considered access and empowerment as a priority area to improve outcomes for disabled children. It introduced a core offer for disabled children and their families, including standards for local authorities regarding the level of involvement of disabled children and young people in decision making about the services they receive (HM Treasury and Department for Education and Skills, 2007).

Valuing People (2001) and Valuing People Now (2009)

The government also highlighted within its white paper on learning disabilities, Valuing People, the principles of rights, independence, choice and inclusion, promoting the use of both advocacy and person-centred approaches for planning with people with learning disabilities (Department of Health, 2001d). Valuing People Now (2009) set out a three year strategy to implement the above principles (Department of Health, 2009).

Working Together, Listening to the Voices of Children and Young People (2008)

Working Together sets out how schools should give young people a say in how decisions that affect them are made. The guidance stated that this should include, for example, the strategic planning and governance of the school, the recruitment and selection of staff, and developments such as peer support (Department for Children, Schools and Families, 2008).

Health care provision

Within health care, service users in general have been given more power in exercising choice and influencing the nature and quality of the services they receive, this also includes children and young people. For example, national requirements for patient and public involvement place a duty on service providers to involve children and young people (Department of Health, 1999b, 2001, 2003a, 2003b, 2003c, Department of Health/Department for Education and Skills, 2004). The Department of Health in 2002 documented in its action plan an expectation that children and young people will be routinely involved in service development at both central government and local level and that this should not be tokenistic.

> *"Participation should go beyond consultation and ensure that children and young people initiate action and make decisions in partnership with adults, for example, making decisions about their care and treatment or in day to day decisions about their lives"* (Department of Health, 2002, p4)

National Service Framework for Children, Young People and Maternity Services (NSF) (2004)

The National Service Framework for Children, Young People and Maternity Services (NSF) in England, published in 2004, set standards aimed at

raising the quality of the health and social care services that children receive (Department of Health and Department for Education and Skills, 2004). The Framework had a broad remit but a central theme stressed the need to consult and involve children and set out very clear guidance on participation. It stated that markers of good practice include disabled children and young people and their families being routinely involved and supported in making informed decisions about treatment, care and support and in shaping services, including in their planning, commissioning and redesign. Specific attention is also given to information provision whereby local authorities, primary care trusts (being disbanded) and NHS trusts should ensure that timely, appropriate, accessible and accurate information is provided to enable children, young people and their parents/carers to make choices about their treatment, care and services they wish to use. The Framework specifically states that children can contribute unique and essential knowledge during decision-making and that their involvement results in the provision of more appropriate services. However, it also notes that disabled children and young people are less actively involved in decision-making than children who are not disabled. Therefore local authorities, primary care trusts and NHS trusts should ensure that they have an ongoing service user involvement programme for disabled children and young people in line with the NHS Patient and Public Involvement and Building on the Best: Choice, Responsiveness and Equity in the NHS Guidance (Department of Health, 2003d).

Standard 8 of the NSF for disabled children and young people and those with complex health needs stated:

> *"Professionals should ensure that disabled children especially children with high communication needs are not excluded from the decision-making process. In particular professionals should consider the needs of children who rely on communication equipment or who use non-verbal communication such as sign language."* (Department of Health/ Department for Education and Skills 2004, p29)

The Framework states that facilities, equipment and skilled workers should be available to enable children, who do not use speech and children who find engagement and interaction difficult, to participate in assessment and decision-making processes.

Healthy lives, Brighter Futures (2009) and You're Welcome Quality Criteria (2006)

Similarly, the Healthy Lives, Brighter Futures strategy for children and young people's health outlines initiatives to strengthen the participation of children and young people and their parents in shaping services (Department of Health and Department for Children, Schools and Families, 2009). The You're Welcome Quality Criteria Toolkit (Department of Health, 2006) includes quality criteria against which services can assess their progress to becoming young people friendly. The criterion includes four specific ones relating to the participation of young people and these were included in the NHS Operating Framework for 2009/10.

World Class Commissioning for Children and Young People (2009)

Of particular significance to the participation of children and young people in decision-making concerning services is the Department of Health guidance on World Class Commissioning for Children and Young People (Department of Health and Department for Children, Schools and Families, 2009). Included within the commissioning competencies are ones relating to engagement of the public and patients, specifically the guidance states that children and young people's involvement should be moving beyond consultation to meaningful roles in priority setting, monitoring and designing services.

Equality and Excellence: Liberating the NHS (2010) and Health and Social Care Act (2012)

In 2010, the coalition government announced a fundamental reform of the NHS. Equality and Excellence: Liberating the NHS included proposals to give patients a greater say about the services they receive (Department of Health, 2010). The subsequent Health and Social Care Act (2012) created a duty on NHS commissioning boards, clinical commissioning groups, and Health and Wellbeing boards to involve patients, carers and the public, and that their views and feedback should form an integral part of local commissioning; how this is operationalised for children and young people is yet to be seen. Specifically, the government's vision for the health of children and young people was set out in Achieving Equity and Excellence for Children (Department of Health, 2010), emphasising the importance of children and young people being offered opportunities to speak of their experiences and what had made a difference to their lives. Some of the proposed changes in this document fed into discussions around the Health and Social Care Act 2012.

The Children and Families Bill (2013)

Most recently, the coalition government have been taking forward proposals to reform the support given to disabled children and those with special educational needs. These proposals were set out in Support and Aspirations: A new approach to Special Educational Needs and Disability Green Paper (2012) and would create a single assessment process for an education, health and social care plan to cover children from birth until 25 years old, they also include further development of personal budgets. Although these proposals are still in discussion at the time of writing, it is expected that they will be introduced into parliament under The Children and Families Bill in 2013. Pressure groups have raised particular concerns about the lack of clarity or emphasis on the participation of disabled children in decision making within these new arrangements. Possibly in response to this, the government have recently formed a Young People's Advisory Group, facilitated by The Council for Disabled Children, to help develop the next stages of these reforms. The government also responded to these concerns within Support and Aspirations: A new approach to Special Educational Needs and Disability, Progress and Next Steps (2012), where they reflected on the importance of disabled children and young people's participation at a local level by stating that they want to give

greater control to disabled children and young people's participation and make them "authors of their own life stories" (p10). They recognised that participation for disabled young people was patchy across the country despite there being clear statutory requirements. They further stated that where they have evidence that a local authority is not fulfilling these duties they will take action to understand the problem, provide links to additional support and where necessary will consider a formal improvement notice.

4.4 Discussion

In the last 20 years there has been considerable recognition in policy of the importance of participation and this should be seen as a positive step forward. Particularly, in recent years, the recognition of the rights, and abilities, of children with complex communication needs and learning disabilities to participate in decision-making processes has been hard fought, and finally recognised. The vast array of guidance illustrates a commitment to disabled children and young people's participation across all aspects of service provision. However, most of the policy is not a legislative requirement, thus implementation is discretionary and there has been piecemeal development. Davis and Watson (2000) argue that this discretion within policy provides a discourse behind which people can claim that they are doing something, but does not allocate an effective voice to disabled children and young people.

Of importance to note is the lack of direct funding to support the development of this practice. When direct funding has been available such as under Quality Protects or Aiming High for Disabled Children, there appears to be a flurry of activity, however, it is difficult to ascertain the extent to which this is maintained once the funding is mainstreamed. On a number of occasions, real opportunities to develop disabled children's participation were missed. For example, the New Labour government committed £5 million between 2008-2011 to support parent/carer participation, but no funding was forthcoming for disabled children and young people. Some commentators would thus argue that the participation of disabled children and young people is more rhetoric than reality (Martin and Franklin, 2009).

In addition, despite such emphasis being placed on disabled children and young people's participation within policy in the past, the current extensive funding cuts will almost certainly affect both well-established practice and any future developments in this area. Those advocating disabled children and young people's rights to involvement in decision-making concerning services appear to face considerable challenges ahead.

5. Research Evidence – Where and which disabled young people are participating

The following chapter presents the available research evidence on the participation of disabled children and young people in decision-making; examining what is known about where disabled young people are participating, who is participating and who are still excluded. Because this evidence is limited, the chapter draws on the wider literature concerning the participation of children and young people generally.

5.1 Participation of children and young people generally

Key messages from generic participation research

> - There is evidence of participation activity across England, but it is variable across services and sectors.
> - There is limited evidence available on the quality of participation or on the impact of participation.
> - Participation is mostly centred on activities seen to have an obvious impact on children e.g. leisure.
> - The last published review of practice, however, concluded that there was an increase in structural mechanisms to involve children and young people in decision-making and a shift in attitudes towards involving young people in decisions.

Generic studies of participation have concluded that there is an array of participation activity across England, although there is variability across different sectors and within service areas, and limited evidence gathered on impact (Cutler and Frost, 2001; Kirby et al, 2003a; Department of Health 2003d; Oldfield and Fowler, 2004; Davey, 2010; Burke 2010). Kirby et al, for example, found that most participation work was locally based, in small organisations or agencies and was most likely to involve generic youth work or community regeneration. Cutler and Frost illustrated how children and young people were most likely to be involved in generating ideas about existing and new policies or services, and were less likely to be involved in service delivery, monitoring or evaluation. In addition, participation was most frequently centred on activities which can be seen to have an obvious impact on children such as leisure, recreation or safety, rather than to be involved in making decisions about broader issues or services such as transport or housing (Oldfield and Fowler, 2004; Davey, 2010).

Willow et al (2004) survey of 100 consultation initiatives involving primary school age children found that despite a large amount of energy and goodwill, there was little to show in return for the time and effort expended. Analysis of the 2006 Children and Young People's Plans illustrated that although consultation had taken place, the level, depth and quality of engagement varied considerably (Lord et al, 2006). Further

analysis of 75 plans in 2008, indicated that children and young people had been consulted in the preparation of every plan, however, there was not sufficient evidence to draw conclusions about the quality of the consultations (Atkinson, 2008).

Evaluations of two government programmes, The Children's Fund (The National Evaluation of the Children's Fund, 2004) and Children's Trusts (University of East Anglia, 2005), which had the participation of children and young people at the core of their work, concluded that the participation of children and young people was variable with a lack of systematic approaches.

Despite a plethora of policies, the government's commitment to children and young people's participation has been repeatedly criticised by the UN Committee reviewing the UK government's implementation of the UNCRC. While recognising the increased emphasis placed on participation by the government, the Committee felt there was still more to do, especially in terms of disabled children's participation and in ensuring that participation leads to change (United Nations, 2008).

Likewise, one of the very few specific evaluations of children's participation, of the Investing in Children initiative, concluded that:

> *"It has been much easier to help young people articulate their experiences into a sound understanding of how public services work and could be improved than it has been to effect and sustain changes in those services and in the attitudes that inform them."* (Williamson, 2003, p7)

The most recent review of participation evidence commissioned by the Office for the Children's Commissioner concluded that since the introduction of The Children Act 2004 significant progress had been made. Evidence suggests a steady rise in the number of structural mechanisms to enable children and young people to participate, and a cultural change in the value children and adults are placing on participation. Yet this was by no means universal across all sectors or afforded to all children and young people; the report highlights that disabled children and young people are one group missing out on developing practice (Davey, 2010).

5.2 Evidence of disabled children and young people's participation in decisions about services

> **Key messages on the participation of disabled children and young people**
>
> - Disabled children and young people have fewer opportunities to participate than their non-disabled peers.
> - Many disabled children and young people are denied opportunities to participate in decisions about their own care and lives, and thus can lack the skills, experience and self-esteem to take part in strategic decision-making.
> - Children with complex communication needs, disabled children from ethnic minority groups and younger disabled children appear to have even fewer opportunities to participate.
> - There are few studies systematically examining levels of participation in strategic decision-making, or examining the impact of participation, for disabled children and young people.
> - Where disabled children have participated, this is usually through consultation or through membership of youth councils/forums, and mainly on issues relating to play or leisure services.
> - There are few examples of disabled children and young people participating in higher levels of decision-making, however, there are some that illustrate how this can be achieved.
> - From the examples of practice, it can be seen that disabled children and young people have much to contribute to the decision-making process and can bring about change.

The extent of disabled children and young people's participation

Although there has been greater emphasis placed on the participation of children and young people and some general evidence to suggest a growth in participation activity, disabled children and young people have fewer opportunities to participate than their non-disabled peers (Council for Disabled Children, 2000; Sinclair and Franklin, 2000; Robbins, 2001; DH/DfES, 2004; Sinclair 2004; Cavet and Sloper, 2004; Franklin and Sloper 2007, 2009; Davey 2010; Burke, 2010). Government recognised this in Standard 8 of the National Service Framework for Children, Young People and Maternity Services identifying that *"disabled children are less actively involved in decision-making than children who are not disabled"* (Department of Health/Department for Education and Skills, 2004, p29). A review of literature undertaken by Cavet and Sloper (2004) concluded that the participation of disabled children needs further development with evidence that good practice is not widespread. Subsequently, Franklin and Sloper reported that practice within social care services was patchy and limited. Small numbers of disabled children and young people were participating and these were in the main considered to be the most articulate, confident and most able to communicate (2007, 2009).

There is slightly more evidence available on the participation of disabled children and young people in decisions about their own lives, although studies invariably conclude that there is patchy practice and that many disabled young people are not adequately involved in decisions which directly affects their lives, for example, with regard to:

- involvement in transition planning (O'Sullivan, 1998; Morris, 1999b, 1999c;Heslop et al, 2002; Cope, 2003; Dee and Bryers, 2003; Ward et al, 2003;; Beresford, 2004; Abbott and Carpenter, 2009; Sloper et al, 2010; Clarke et al, 2011)
- in health care settings (Stalker et al, 2003)
- decisions about residential school and reviews at residential schools (Abbott et al, 2000)
- involvement in reviews (Franklin and Osborne, 2009)
- access to advocacy (The Children's Society, 2007; Franklin and Knight, 2011).

Although individual decision-making is not the focus of this report, these participation activities cannot be seen as separate entities, if disabled children are not taking part in decisions about their own life, then it is a long leap for them to have the skills, confidence, self-esteem and empowerment to be able to participate in decisions about services. As Beresford (2002) argues:

> *"Ongoing denial of the right to be heard affects the skills and confidence children and young people acquire in their abilities (and expectations) to make their views heard and to make choices and decisions."* (p157)

Less attention has been placed on disabled children and young people's participation in collective decision making. There have been very few studies specifically examining the participation of disabled children and young people within strategic level decision-making about services. One of the few, a study examining the participation of disabled children in social care services, surveyed local authorities. Only 57 out of 71 local authorities who responded indicated that disabled children and young people had participated in this arena. The study also concluded that disabled children were most likely to be consulted about play or leisure services (Franklin and Sloper, 2006). Lightfoot and Sloper (2003) investigated the extent and nature of involvement of physically disabled and/or chronically ill children and young people in health service development. They surveyed all local health authorities and NHS health trusts and identified 27 initiatives across England. These included seeking their views to inform developments in: hospital inpatient, outpatient and community services, transition to adult services, and information needs for disabled young people. Seventeen of the initiatives reported that children's involvement had resulted in changes; 11 reported that they went beyond consultation to involve children in the actual decision-making process about services. However, only a third of these initiatives had someone with designated responsibility for this work. Although this is now dated and can only provide a snapshot in time, it did illustrate the very small number of participation opportunities for this group of young people.

Coad and Houston (2006) reviewed the literature on the involvement of children and young people in decision-making processes within healthcare services. They concluded that there were many positive examples of consultations with children with health conditions, but there was a scarcity of published literature and evaluative reports of how children had been involved in decisions about heath services and the subsequent impact of their involvement. (Examples of health consultations include: Farnfield and Kaszap, 1998; Sartin et al, 2000; Dixon-Woods et al, 2002; Carney et al, 2003; Young et al, 2003; Battrick and Gasper, 2004; Hallstron and Elander, 2004; Coyne, 2006).

Knight et al (2006) undertook a review of consultations undertaken with children and young people with learning disabilities about the support they receive. They identified relatively small numbers of studies which had focused on this issue. Those consultations which had taken place had usually centred on a particular service children and young people were attending or receiving, such as:

- short breaks (Minkes et al, 1994; Marchant et al, 1999a, 1999b; Prewett, 1999; Crisp et al, 2000; Preece, 2002;)
- being looked after (Morris, 1995; 1998b, 1998c; Knight 1998)
- transition to adult services (Morris, 1999a, 1999b; Heslop et al, 2002; Ward et al, 2003, literature reviewed by Beresford 2004)
- play and out of school experiences (Petrie et al, 2000; Clark and Moss, 2001; Petrie et at, 2002).

Both the academic community and voluntary sector have published an ever increasing library of examples of disabled children and young people expressing their views about the services they receive and what improvements they would like to see, however, it is unknown whether these initiatives lead to change or influences decisions being made.

Davey's generic analysis of participation activity concluded that children and young people were most likely to be engaged in consultations or were members of youth councils or youth forums (Davey, 2010). From the limited evidence available, it appears that similar conclusions can be made of disabled children and young people, albeit that progress is at a slower pace. The research evidence illustrates a number of local authorities funded one-off consultations and structured forums such as disabled young people's participation groups. Some groups appear to be directly linked into strategic decision making boards such as transition strategy boards within local authorities.

Sloper et al (2010) carried out a study of multi-agency transition services for disabled young people and identified that their involvement in planning and overseeing services was less developed than that of parent participation. Fifteen services out of 34 stated that they involved disabled young people in planning services and 12 of them stated that they involved disabled young people in overseeing the service. Examples of what this equated to varied from involvement in the recruitment of a key worker and preparing an accessible version of a transition strategy, to involving young

people in producing a DVD on their experiences to inform good practice and involving young people in the development of a website. However, the authors concluded that these examples appeared to be quite innovative practice as most authorities reported undertaking consultations. Overseeing the transition service consisted mainly of inviting disabled young people to be members of transition strategy boards. However, practitioners taking part in Sloper et al's study reported concerns about involving disabled young people on steering groups. Their concerns centred on the resource and capacity implications of making meetings accessible (for example, producing accessible minutes of meetings, supporting the young people before, during and after the meeting), and the possibility that if disabled young people were involved in the meeting that it would have to be pitched at a level that would limit their usefulness and productivity. Others stated that young people would struggle to engage, find the meeting intimidating and not gain any personal benefit from attending. Some raised questions over the representativeness of two young people to represent the views/experiences and opinions of the diverse range of disabled young people. Others, however, thought that the costs of supporting young people to participate were justifiable and worthwhile. Spicer and Evans (2006) report similar findings in their study on children's participation in strategic processes concerning the Children's Fund initiative. They highlight how strategic stakeholders opted for consultation rather than involving young people in the actual decision making process.

Overall, there is little evidence on the extent, variability or equitability of participation activities and on whether they actually lead to changes in services. The few reports available present a mixed picture and suggest that there may be some way to go before these become empowering forums for disabled children and young people. For example, a Commission for Social Care Inspection (CSCI) report on transition for young people with complex needs concluded that there was limited practice, yet positive feedback from senior managers when it did happen. Just over a third of councils reported some changes through parent and young people's involvement such as new protocols, improved information for young people and their families, person-centred approaches to planning transition and access to services. Unfortunately it is impossible to know whether such changes were brought about through the parents participating or the children (CSCI, 2007).

Disabled children and young people's participation at a strategic level

Amongst the literature there are a few examples of disabled children and young people taking part in participation at a higher level and being empowered to fully be involved in the decision-making process.

One example is Ask Us!, a national peer research project of disabled children and young people, undertaken by The Children's Society, and evaluated by the Joseph Rowntree Foundation (The Children's Society, 2001). Ask Us! arose from the Department of Health's National Disability Reference Group for the Quality Protects programme. It consisted of a national consultation of over 200 disabled children and young people,

including some with complex health needs and communication needs. Six local CD Roms were produced by disabled children and young people each focusing on different areas of exclusion, such as access to play, leisure and education and relationships with friends and families. A summary CD Rom of key messages was also compiled with the aim of targeting key people in local and national government to seek wider changes in attitudes and services. A second phase, funded by the Department of Health was also undertaken with 180 disabled young people and involved eight local consultations. This resulted in a second summary CD Rom charting the practical changes needed to fulfil young people's rights (The Children's Society, 2001; Willow, 2002).The evaluation of Ask Us! included the views and experiences of the young people who were researchers and contributors, and included an evaluation of the impact on external systems and services via questionnaires sent to those who bought, or had seen, the CD Rom. Results illustrated that the use of multi-media and production of a CD Rom had been an excellent means of enabling disabled young people to communicate their views. Locally some changes were made in services as a result. For example in Solihull, £30,000 worth of play equipment was secured by the children and young people involved. Badham (2004) concluded that this programme had made an impact because of sustained contact, a build up of trust, recognition of mutual benefit, time, the young people taking charge of the medium and the message, and working within the social model of disability. The social model of disability is explored further in section 6.5.

More recently, Kellet (2010) reported on research undertaken by a group of young people with learning disabilities. The driver for this research came from a concern about the lack of meaningful participation for young people with learning disabilities in youth-decision making forums. Mencap initiated and funded the project following concerns that members of their youth groups were not being empowered in the various local authority youth forums and councils in which they participated. Six young people aged 14 to 19 were supported to undertake the research project. Following research training, the young people scoped the project, designed research instruments, collected and analysed the data and produced findings concerning the barriers they faced to meaningful participation; *things that got in the way of them understanding"*, *"things that got in the way of them being listened to"* and *"things that got in the way of them actively participating".* The young people were then actively involved in the report writing, and designing and evaluating a toolkit to address some of the barriers that they had identified.

A further example of young disabled people being empowered to undertake their own research includes a group who called themselves Educable. In this instance, disabled young people were empowered to choose a research topic themselves thus not undertaking predetermined adult defined research (2000).

Similarly, ALLFIE (Alliance for Inclusive Education), a disabled people's led organisation undertook research into disabled children's experiences of school, employing a young disabled project worker and utilising the advice of a group of young disabled people (Wilson and Jade, 1999). This same

organisation has also undertaken research into ways different organisations include disabled young people and encourage their leadership (O'Mahony, 2010).

One of the few examples of disabled children and young people taking part in the evaluation of services was undertaken by Greco et al (2009). (For the full report see Beresford et al 2008). This study sought the views of D/deaf children and young people using a specialist mental health service. The evaluators report using a variety of tools to facilitate the interviews of children thus reducing reliance on communication and literacy. Two or more different approaches were used to explore key issues. In addition, children were given a choice whether to be interviewed by a deaf or hearing researcher and which language they used i.e. BSL (British Sign Language), English or Signed Supported English.

The Royal College of Paediatrics and Child Health showcased some examples of participation within their guide: Not just a phase (2010). This included the Staying Positive, a self-management course giving young people the confidence, skills and knowledge to manage their health condition and be more in control if their lives. The course was delivered entirely by young people. Other examples included within the guide concerned involvement in: the design of the built environment, staff recruitment, governance and influencing the health care research agenda. Similarly, Making Ourselves Heard report on examples of participation within services. They illustrate examples of disabled children being involved in recruitment and selection of local authority staff, inspecting youth services, promoting disability equality in schools and forming youth forums in local authorities in order to influence service provision (2009).

As already indicated, the previous New Labour government provided funding for the development of short break services for disabled children and their families under the Aiming High for Disabled Children initiative; this also led to the proliferation of participation opportunities for disabled children and young people. Together for Disabled Children undertook a survey of services and concluded from the data that this had been "*a catalyst for change*" and that it had:

> "...*allowed, sometimes for the first time, groups of disabled children to come together and be supported, by well-trained staff, to begin to shape and influence the type of services that they need to support them to have 'fun' and live 'normal lives'.*" (2010, p3).

The report also considers the impact that this participation has had on commissioning. However, there was less optimism amongst respondents that this work would continue in the longer term and they had concerns about its sustainability. The report also includes a number of examples of practice described as being innovative. Support for these findings also comes from Greig et al's evaluation of the short break pathfinders, where they concluded that:

"... *involving disabled children in service design, development and evaluation is leading to more accessible and child focussed short breaks*." (Greig et al 2010, p11).

5.3 Who is participating in disabled children's participation and does this matter?

> **Key messages on who is participating in disabled children's participation**
>
> - ➢ It is important to examine who is participating as disabled children are not a single, homogenous group.
> - ➢ There is little information collected on the characteristics of children participating.
> - ➢ Younger disabled children, children with communication needs, looked after disabled children, and children with complex health needs were even less likely to participate in decision making.
> - ➢ Disabled children from ethnic minority groups faced additional cultural and linguistic barriers to involvement.
> - ➢ Only small numbers of disabled children are participating in decisions about services, generally they are in forums/groups of under ten, such small numbers does raise some issues concerning representativeness and accountability to other children.
> - ➢ The processes and methods used to recruit disabled children and to facilitate decision making will affect who participates.
> - ➢ There are few mainstream decision making opportunities for disabled children, and disabled children's views are missing within other decision making arenas afforded to, for example, looked after children.

It is important to recognise that disabled children are not a single, homogenous group. They differ in personal circumstances (age, sex, ethnicity, culture, impairment, social and economic circumstances) and in their interest and capacities. All of these factors have a bearing on their abilities to participate and what they bring to the decision-making process. In addition, many children "labelled" as disabled or who might fall under definitions of disability might not consider themselves to be disabled and indeed strongly reject this identity. Lewis et al (2005) reported that the young people they interviewed, which included young people in mainstream and special school settings, did not dismiss an identity of being a disabled person, nor did they consider it to be particularly important, choosing instead to view their identities in terms of future roles and employment aspirations. A discussion of this complex issue is beyond this paper, however, this does raise considerations for participation. For instance:

- Which young people come forward to participate in decisions when it is advertised as for disabled children or concerning disability issues?

- Are they representative of all disabled children who might be defined as such under the Equality Act (2010) definition of disability[2]?

---

[2] The Act defines disability as someone who has a physical or mental impairment which has a substantial or long-term adverse effect on that person's ability to carry out normal day-to-day activities.

Despite the growth in participation activity there is still limited evidence on the characteristics of which children and young people are being involved in participation activity, few studies record such information, making differentiation impossible. The limited evidence available on children and young people's participation more generally suggests that certain groups are less likely to be involved. Kirby and Bryson (2002), in their review of 27 research studies on participation, noted that older young people were more likely to be involved than younger ones, and girls were more likely to be involved than boys. Younger children, children and young people with communication needs and those with minimum involvement with local agencies were identified as least likely participants by Sinclair (2004). Oldfield and Fowler's (2004) mapping of participation activity in England indicated that young people aged 14 – 19 were most likely to participate and there were relatively low levels of involvement of children under the age of six years. Davey(2010) also reports on the lack of involvement of children under eight years.

There is limited evidence to establish whether such patterns exist amongst the participating population of disabled children and young people, although anecdotal evidence suggests this is the case. Cavet and Sloper's (2004) review of literature revealed that some disabled children had not been afforded their full participation rights under the Children Act 1989 or the UNCRC, for example, in particular ventilator dependent young people (Noyes, 2000); those looked after by the local authority (Morris, 1998a, 1998c); and, those with severe impairments (Lightfoot and Sloper, 2003). In addition, the lack of availability of communication aids to those children who rely on them has been reported as presenting obstacles and limiting children's involvement in decision-making (Morris, 1998a; Stone, 2001; Rabiee et al, 2001). Marchant and Jones (2003) noted the linguistic and cultural barriers to involvement faced by disabled children and young people from ethnic minority groups. Franklin and Sloper's (2006, 2007) survey of local authorities illustrated that there was wide variation in the numbers of children participating in decisions about services. Across authorities numbers varied from less than ten to over 50, however, a third of the initiatives only involved up to ten young people. In addition, the small number of disabled children participating were in the main the most able to communicate, most articulate and most confident. Lightfoot and Sloper (2003) found similar patterns within their examination of participation in health service development for physically disabled young people and those with chronic illnesses. Generally, young people participating were aged 12–18 years, and 30% of initiatives were involving less than ten children.

Sinclair (2004) states that participation practitioners have to ask how the processes and mechanisms that they use influence who gets involved and who is excluded. For example, there may be significant differences in who is involved depending on whether children are elected to participate, are self-elected, or selected by adults. Similarly different children and young people may be involved if the method of participation requires access to certain skills or resources, depends on getting to certain venues, on coming out of school or being fluent in English. Thus it is important to examine how participation is embraced, understood and facilitated in order to develop

truly inclusive participation practice. This is important to consider given the social exclusion and barriers to inclusion that many disabled children and young people face.

In addition, the numbers of children and young people who become involved vary enormously by participation activity. Many formal participation activities enable only a small number of children and young people to get involved (e.g. councils, youth forums). Sinclair (2004) raises the issue of representativeness of children and young people participating in activities such as youth forums, particularly as in some cases only a handful of young people are participating. Representativeness to some extent depends on the purpose of the activity. If the focus of participation is to give generalised representation to the views of children as a whole, then it is vitally important. If it is to broaden the range of perspectives that are informing decision-making, for example, in an on-going forum, then statistical representativeness may be of less relevance. However, organisations need to be clear about this issue. Sinclair poses highly relevant questions which facilitators of participation need to examine:

- who does the child or the child's views represent?
- are children being asked to draw on their personal experiences or do we expect or enable them to speak on behalf of larger groups of children?
- are we always clear about this?
- how do we support children in representing the views of other children without the risk of them becoming "professional children"?

Likewise, Lansdown (2006) offers advice to avoid the pitfalls of engaging with such a small number of children and suggests that the following needs careful consideration:

- the way in which children are selected
- the nature of their accountability to children within their local community
- the support given to them to forge links between the issues raised in these arenas and their translation into action on the ground
- the need to create opportunities for the widest possible numbers of children to participate at this level.

These questions are particularly pertinent in terms of inclusivity of disabled children and young people within "mainstream" participation activities. For example, if such small numbers of children and young people are involved generally, the likelihood of disabled children and young people being represented on these forums (when not specifically addressing disability issues) is quite minimal. This is particularly likely to be so when we consider the barriers disabled children and young people face in accessing mainstream activities and how "invisible" disabled children and young people often are in mainstream services. In addition, it appears that there has been the creation of silos of participation, whereby the "voices" of minorities within minority groups are not being represented. For example, disabled children are not adequately represented with the participating population of looked after children, and they appear to be invisible within,

for example, the participation of refugee and asylum seeking children, children within the criminal justice system, or children with mental health issues.

6. Research evidence - Barriers affecting the participation of disabled children and young people

The following chapter explores the available evidence on the key barriers that affects disabled children and young people's participation. The evidence indicates that there is a lack of accessible information and access to communication methods. This is coupled with limited numbers of people who understand communication takes many forms. In addition, disabled young people can often have limited experiences of decision-making in their own life and many systems and mechanisms to facilitate children's involvement are not made accessible. These barriers are further exacerbated by negative attitudes and structural barriers which leaves many disabled children and young people excluded from the decision making process.

Key barriers affecting participation

➢ Children with communication needs face barriers to participation because of a lack of access to communication.
➢ Disabled children have a lack of opportunities to participate in decisions concerning their own life and thus opportunities to develop the skills, experience and confidence to participate.
➢ A lack of accessible and appropriate information disempowers disabled children and young people from participating.
➢ There still exists persistent negative attitudes towards the participation of disabled children in decision-making.
➢ The continued dominance of the medical model of disability means that barriers faced by disabled children to participate are not addressed.
➢ There is a lack of time and resources being dedicated to facilitating participation.
➢ There is a lack of skills development, training and support being provided for practitioners and disabled children and young people.
➢ There appears to be too much emphasis being placed on formal approaches to participation and not enough opportunities to implement informal participation mechanisms, which children would welcome.
➢ Many mechanisms for participation, such as complaints procedures, are not being made accessible to disabled children and young people.

Research evidence illustrates that, despite policy and commitment to children's participation, achieving this in a sustainable and meaningful way is challenging (see for example, Alderson and Montgomery, 1996; Alderson, 2000; Willow, 2002). McNeish and Newman (2002) summarise that involving young people in decision-making processes:

- takes time
- involves developing new skills for adults and young people
- requires an investment of resources

- can entail a major shift of attitude on the part of organisations
- like any process of negotiation, it can make decision-making slower.

Morris (2003) reflecting on her experiences of four projects, which sought the views of disabled children and young people including those with significant communication and/or cognitive impairments, outlined barriers to identifying and meeting young people's communication needs. These concerned:

- The gatekeeper (i.e. person with whom they were negotiating access to the young person) not having enough knowledge of the child's communication needs.

- Assuming that the researchers would just be asking questions of a parent or staff member, rather than seeking information from the young person themselves.

- Being told that there is no point in trying to include the young person as, for example, "*he won't be able to tell you anything*". This is not uncommon, a number of researchers have expressed concerns that parents can act as barriers, being more willing to take part in research themselves than letting their child take part (see for example: Minkes et al, 1994; Lewis and Porter, 2004).

The following section collates the evidence from the literature on the barriers to participation that many disabled children and young people face. Some of which are barriers faced particularly by disabled children and young people, whilst others can be seen to be difficulties faced by any child or young person because of their status as children.

6.1 Access to communication

Consistently throughout the literature it is reported that children and young people with communication needs face additional barriers affecting their participation:

- a lack of access to communication systems and methods
- a lack of people around them who understand their communication method or who are willing to learn or "give it a go"
- not being given enough time and support to communicate
- children and young people with communication impairments may not always be visible
- negative attitudes prevailing that those who do not use speech to communicate cannot express their views or that speech is the only way to communicate
- underestimating a child's ability to communicate and/or having low expectations.

All of the above are identified as barriers within, for example, the following studies: Stalker et al, with regard to safeguarding (2010); Morris 1998b, 1998c; Franklin and Sloper 2006, 2007, 2009 with regard to disabled children's decision making; Franklin and Osborne (2009)

with reference to independent reviewing officers; Franklin and Knight, (2011) in terms of advocacy for disabled children.

Evidence within Franklin and Sloper's studies (2006, 2007, 2009) identified that many social workers reported that they were unsure of the communication methods of children on their case-loads. Morris (1998b) reported in her study of children and young people living in residential homes and schools, that where children had very limited or no use of verbal language, or were seen as having a high level of impairment, little effort had been made to find alternative methods of communication. Morris states:

> *"One of the most disabling attitudes faced by children with physical or sensory impairments and particularly by children with significant learning difficulties, is the assumption that they do not have a view to express or a way of expressing it. Our society operates as if communication only takes place through written or spoken language"* (1998b, p36)

Davey (2010) highlights how health professionals often struggle to communicate effectively with disabled children and young people, causing stress and anxiety for children. Social workers report the same difficulties, highlighting their lack of skills, training, knowledge and experience in consulting and communicating with disabled children (Franklin and Sloper 2006, 2007, 2009). Similarly, independent reviewing officers expressed their concerns in a Department for Children Schools and Families investigation (Franklin and Osborne, 2009) and advocates had similar worries (Franklin and Knight, 2011).

There are a number of guides on how to facilitate communication; however, professionals repeatedly report that time with a child is restricted and thus opportunities to understand a child's communication and develop communication skills are severely limited.[3]

Throughout the many consultations with disabled children and young people undertaken by the academic community and voluntary sector, a consistent theme is young people's concerns about being able to communicate their views. They have emphasised that it is crucial to be supported to communicate in whatever way they can in order to start making choices and gain as much independence as possible from an early age. Communication is central to social inclusion. Increasing numbers of disabled children and young people use alternative communication systems, for example, symbol boards or computer assisted systems. Yet anecdotal evidence suggests that many children only have access to these systems at school and they are not available or allowed to use them in other settings, thus reducing their opportunities to be involved in decision-making.

---

[3] For guidance see for example: Morris (2002), Martin (2008) and materials contained on the Communication Trust website www.thecommunicationtrust.org.uk

6.2 Experiences of decision-making in own life

As already discussed opportunities for disabled children and young people to make decisions and take control over their own lives is often limited. Bignall and Butt (2000) highlight how young black disabled people view exercising choice and control as a vital component of independence, feeling valued and included; yet these young people often felt excluded from decisions which affected them.

Morris (1995) highlights how access to independent advocacy is a key factor in enabling disabled children and young people to be involved in decision-making. The Children's Society has published two studies identifying that disabled children are being denied access to vital advocacy services, concluding that less than three percent of disabled children in England have access to an independent advocate (The Children's Society 2007a; Franklin and Knight, 2011).

All of the available evidence indicates the importance of nurturing and facilitating self-expression in children and enabling decision-making to be part of everyday relationships and activities between adults and children. This will enable children to develop their capacity to make choices and express their feelings, thoughts and preferences and feel that their views are valued (Martin, 2008). As already argued, the level of competence required to participate at different levels will depend on the individual child, the context and type of decision being made. Children and young people develop different capacities as they get older but they will do so at different times, in different ways and as a result of different circumstances, therefore development stages are fluid. Their ability and exposure to being listened to and making decisions as well as the context will affect their competency to participate. Thus it is important to develop these skills from an early age. As Lansdown (2006) argues denying children opportunities for taking responsibility serves to diminish the opportunity to develop the capacities for doing so, and the subsequent lack of capacity is then used to justify the original failure to allow children greater responsibility.

Willow (2002) points out that it is not unusual for children and young people to internalise beliefs that they cannot take part in certain activities because of a lack of skill or competency rather than because they have not had the opportunity or encouragement. A particular problem she notes for disabled young people or younger children whose contribution and capacities are frequently ignored or underestimated. Lansdown (1995) points out that without a culture of participation, we cannot expect children and young people who are not used to being listened to, to suddenly acquire the skills and confidence to articulate their views at a point of crisis in their lives or expect adults to listen effectively when it is not part of the normal expectation in society. This is particularly pertinent for many disabled children and young people who through social exclusion and the disabling attitudes of others may have been denied opportunities to participate in decision-making and have little experience of choice making within their own life. Similarly, Morris (2001a, 2001b) reports on how disabled children and young people's limited opportunities to participate in society can act as a barrier to involvement. Limited life experiences can

limit understanding or imagination of what might be possible. For example, without experiencing youth provision, it can be difficult to say what you might like to do or what should be provided.

From such a disempowered position, it would be a challenge to suddenly be expected to take part in strategic decision making without support. Yet evidence suggests often such support can be minimal and variable (Franklin and Sloper, 2007).

6.3 Provision and need for accessible information

> *"Access to information is central to promoting and supporting inclusion. Information is fundamental for disabled children to manage their day-to-day lives, to make informed decisions, to provide informed consent, to make choices and to plan for the future."* *(Beresford,2002, p154)*

Genuine participation is based on informed consent and requires full and accessible information about the decisions to be made and/or the participation activity. Children cannot participate in decisions if they are not fully informed of the options available to them and the implications of those options (Alderson and Montgomery, 1996; Beresford and Sloper, 1999; Franklin and Sloper, 2009). Article 13 of the UNCRC grants children the right to express, seek and receive information in any medium they wish. This emphasis on provision of appropriate means of communication is of particular significance to disabled children and young people, especially those with communication needs or sensory impairments. The Department of Health states explicitly that a child who has a learning disability should not be assumed to lack competence:

> *"Many children will be competent if information is presented in an appropriate way and they are supported through the decision-making process."* (Department of Health, 2001, p4)

The need to improve access to information was highlighted in Aiming High for Disabled Children and was seen as vital to the empowerment of disabled children and their parents (HM Treasury and Department for Education and Skills, 2007b). Yet routinely disabled children and young people report that information relevant to their own lives is lacking, for example, information on the services which are available to them. In addition, general information which would be available to their peers is often inaccessible.

There has been some research into the information needs of children with chronic illness. For example, Bradding and Horstman (1999) found that chronically ill children had information needs within four domains: diagnosis, treatment, prognosis and support. In all domains the need for honest and accurate information given within a supportive environment was evident. Beresford and Sloper (1999) researched the information needs of young people with chronic conditions and highlighted the importance of psychosocial information, such as information on dealing with the effects of their condition in social settings, as well as medical information. Danso et al (2003) cite literature which indicates that children and young people within

social care lack information about the reasons for social services involvement, their rights, plans for their care, reasons for decisions made about them and their entitlements particularly as care leavers (Grimshaw and Sinclair, 1997; Hill, 1997; Utting, 1997; Horgan, 1998; Aldgate and Statham, 2001; Cashmore, 2002). For disabled children and young people a lack of information on the following is reported:

- advocacy services (Franklin and Knight, 2011)
- housing options (Dean, 2003)
- transition (Beresford, 2004; Tarleton et al, 2005; Abbot and Carpenter, 2009; Sloper at al, 2010; Clarke et al, 2011)
- leisure and inclusive activities outside school (Beresford and Clarke, 2009)
- leaving care (Priestley et al, 2003)
- information for young ventilator dependent people (Noyes, 2000) and children and young people with hidden disabilities (Cavet, 2000).

The above list is by no means exhaustive.

Most recently, Sloper et al 's (2010) study of transition services identified shocking levels of unmet information needs amongst disabled young people who had access to multi-agency transition services. In this study, parents/carers whose children were going through transition reported their child needed more information on the following areas: communication, self-care needs, further education and training, social care needs, housing, career/employment opportunities, leisure and social life, independent living skills, benefits and finance, transport, transfer to adult health services, short breaks, adult relationships and sex education, emotional changes associated with growing up, support to prepare for transition, advocacy, expressing their view and identifying and achieving future goals. In each of these categories, over 70% of parents reported unmet need. Young people themselves also reported the same high levels of unmet information needs. Post-transition, parents and carers reported similarly high levels of unmet information needs across all of these categories.

Dixon-Woods et al (1999) state that there is a scarcity of evidence about how to design information materials for children. The evidence submitted for this review illustrates that often groups of disabled young people choose to make DVDs or other accessible outputs in order to share information with their peers. However, evidence on children's experience of the process of information sharing is limited, for example, little is known as to whether their information needs are met when they have been involved in decision-making.

6.4 Access to mechanisms to allow children and young people to express their views

Genuine participation requires that a child's view is listened to. There is now widespread acknowledgement, particularly within the care system, that children and young people's safety relies on them being listened to and involved in decisions, both about their own lives and also in general policy and service development (Utting, 1997; Waterhouse, 2000; Laming, 2003).

Moves have been made to create structures that allow children and young people to voice issues of concern or complain about services or treatment. Both the 1989 Children Act and the 1990 NHS and Community Care Act established a duty on the part of service providers to provide transparent complaints procedures. However, such procedures have been widely criticised for being adult orientated, inaccessible, lacking in confidentiality and difficult to negotiate without the support of an advocate (Utting, 1997; Aiers and Kettle, 1998; Oliver, 2003). However, a lack of advocacy services for disabled children and young people has already been evidenced (Franklin and Knight, 2011).

Patient Advice and Liaison Services (PALS) have been established within all English NHS (National Health Service) and Primary Care Trusts, to provide an easily accessible service for people with concerns about their care. However, research suggest that PALS have, so far, provided a generic service, and many have not provided a service that is accessible to children and young people (Heaton and Sloper, 2004). The National Service Framework for Children, Young People and Maternity Services placed value on PALS and advocated that this service is promoted and made accessible to disabled children and young people and their families (Department of Health/Department for Education and Skills, 2004).

Nevertheless, there have been a few attempts made to make mechanisms for complaints accessible to disabled children. For example, MENCAP (2003) developed a resource pack to assist children and young people with a learning disability to complain about the services they use. In addition, within the recently produced government Green Paper on Special Educational Needs and Disability (SEND) (Department for Education, 2012), there is a commitment to creating the right for disabled children and those with special educational needs to appeal to the SEND tribunal. How this will work in practice is yet to be seen.

Some literature points to the necessity of not only formal mechanisms, such as complaints or youth forums, through which children and young people can participate, but also the need for informal approaches – a listening culture, where children can voice their views and be listened to at any time (McNeish and Newman, 2002; Lightfoot and Sloper, 2002a, 2002b, 2003; Kirby et al, 2003a, 2003b - see Figure 2).

Figure 2:   Listening Mechanisms

Informal listening	Formal Listening
- On-going dialogue - Observation - Listening to spontaneous communication - Engaging in joint activities	- Dedicated mechanisms and activities such as one-off consultations, regular group meetings, suggestions boxes

(Kirby et al, 2003a, p27)

Participation studies in the main concentrate on formal mechanisms, but Lightfoot and Sloper's studies (2002a, 2002b, 2003) found that young people urged an informal approach, in addition to formal structures and

dedicated participation workers. This is an important point to reiterate particularly for some disabled children and young people whose communication may take a number of forms. Formal structured mechanisms may not be accessible, and understanding that participation includes methods such as observation or play is often lacking. For some children and young people with complex needs, adults observing, for example, their behaviour or body language in a number of settings can provide a wealth of information and can be used to inform the decision-making process. Similarly, joining in with activities that the child or young person is undertaking can place a child at ease and be more willing to engage and express themselves (Morris, 1998a, 2003; Marchant et al, 1999a; Marchant and Jones 2003). Observation, however, demands specific skills including the need to distinguish between observed events and interpretation of events. The role of the observer also needs to be carefully considered and negotiated to ensure children and young people do not become subjected to additional surveillance, a particular issue for many disabled children. In addition, as Clark (2004) argues listening as part of an ongoing process presents a challenge to policymakers as the outcomes will be open-ended and open to change, thus not a fixed one-off event to meet a prescribed target. Even when a child or young person can take part in a more formal interview, spending time with them when they are engaged in other activities often opens up more opportunities for finding out about their views or experiences. Marchant et al (1999a) describes how some of the best communication can take place when young people do other things at the same time such as drawing or being driven in a car.

There is a dearth of evidence on the extent to which this kind of informal participation is occurring and the outcomes of it. It can be subtle and therefore not register as participation as such.

Non-instructed advocacy is one mechanism which enables the views of those children with complex communication needs to be considered within decision-making processes. Advocacy can include expressing a child's view on their behalf to help their participation in decision-making, and this may be even if the advocate does not agree with what the child or young person is saying or does not think that these views are in the child's best interests - advocates act on the permission and instructions of children and young people. However, for advocates working with disabled young people who have complex communication needs defining advocacy in this way poses major problems. Acting for someone who cannot tell you directly what they think or feel has been called non-instructed or non-directed advocacy and most advocates working with disabled young people with complex communication needs find themselves practising this type of advocacy. Typically non-instructed advocacy involves observation, questioning, information-gathering, clarifying the rights of the child and presenting this information on behalf of the child or young person. Yet practising non-instructed advocacy could also be described as acting in someone's best interests rather than advocating for them in the truest sense and thus is not without its critics (for a fuller discussion of this practice see Franklin and Knight, 2011).

Overall the published literature identifies a number of barriers that prevent effective participation, these can be grouped into attitudinal and practical barriers; these barriers are not mutually exclusive.

6.5 Negative attitudinal barriers

Theoretical debates on the status of children

Consistently throughout the literature there are reoccurring themes identifying negative adult attitudes towards children and young people. These include: the absence of value and status placed on children as children rather than on what they will become; perpetuating attitudes of children as incompetent; an unwillingness to adopt a rights based approach to participation and unwillingness to share power. For example, the literature asks: do adults see children as having rights or just as vulnerable "people in the making", welfare dependent who need care and protection, and who are not yet ready to have rights? Or should they be regarded as young citizens who are entitled to respect and to participate in decisions concerning them? (Willow et al, 2004).

As Willow et al (2004) argue seeing children and young people through the "*lens of citizenship*", rather than as welfare dependent, gives a different picture where young people's strengths and competencies are recognised and their experiences and interactions are considered, as illustrated in Figure 3.

Figure 3: Attitudes towards children and young people

Children as welfare dependents	*Children as young citizens*
➢ Children are dependents ➢ Children are incompetent and vulnerable ➢ Children need care protection and guidance ➢ Children's childhoods are determined by adults	➢ Children are people ➢ Children have strengths and competencies ➢ Children need recognition, respect and participation ➢ Children influence their own childhoods

(p7)

Willow (2002, p38) summarises the barriers to children's participation in the following way:

Figure 4: Barriers to children and young people's participation

Children as the source of the problem	*Adults as the source of the problem*
➢ Children and young people do not have the competence to make decisions ➢ Children need to be protected from decision-making ➢ Children do not want to be included	➢ Adults do not know how to include children ➢ Adults fear losing control ➢ Adults want to be in charge and do not want to include children

Although there is a lot of rhetoric supporting participation, academics have questioned how this has translated into policy and have examined the underpinning ideologies behind some of the major policy decisions concerning children. Martin and Franklin (2009) set out the current theoretical debates concerning the conflicts and dilemmas posed by macro level child policy within England, and how this impacts on disabled children's participation. Drawing on the academic debates concerning how children are constructed within policies such as Every Child Matters (DfES, 2003), the strong emphasis placed within policy on educational attainment, models of social investment, and the focus on children for who they will be in future (and what they will contribute to the economy), Martin and Franklin argue that this poses a number of additional challenges for disabled children and young people. For example, some disabled young people may not achieve high academic attainments, but will nevertheless achieve in other ways (see also Williams, 2004).

Children's competence to participate in decisions

Martin and Franklin also discuss how the continued tension concerning children's perceived competence to participate adversely affects disabled children. Children's participation often rests in the hands of adults perceptions about their ability to participate and is thus subject to the inherent power imbalance that exists between adults and children. Disabled children are frequently disempowered. They experience discrimination and oppression on the grounds of being not only a child, but also of being disabled. Compared to their non-disabled peers, disabled children and young people experience multiple discrimination, low expectations and social exclusion (Russell, 2003; Davis et al, 2005). This is compounded by the fact that disabled children are constructed in policy as vulnerable (Priestley, 2000) and often have to pronounce "difference" to get the support to be "included" (Davis et al, 2005). Disabled children and young people, particularly those with communication needs, continue to be defined by what they cannot do, rather than what they can do (Rabiee et al, 2005a), again impacting upon their right to be regarded as competent to participate in decision-making. This construction of disabled children as vulnerable and the discourse this creates impacts upon professionals' attitudes towards disabled children and is often reflected in the power adults exert over children. Power can present a significant barrier to meaningful participation. Issues of power, including both adult/child relations and the structural power of organizations and its impact on participation, do not receive adequate attention (Badham, 2004; Cockburn, 2005. Power relations can impact on disabled children and young people disproportionately, as many will be subject to increased surveillance in their lives, leading to increased adult control (Priestley, 2000). This can create additional barriers to participation for disabled children and young people who may often have to rely on the willingness of adults to facilitate and support them to access the opportunities to participate.

Medical and social models of disability

In addition the continued dominance of the medical model of disability creates barriers for disabled children and young people's participation

(Morris 1998b; Beresford, 2002). This medical model individualises the issue of disability into personal deficits of the body or mind. Alternatively, the social model of disability, developed during the 1970s, defines disability as the social restriction placed on people with impairments by society. Thus people are disabled by discrimination, prejudice and by a society that fails to address their needs in terms of social relations and structures, and not by their bodies or as a result of their individual impairments (Oliver, 1983). Beresford (2002) argues that the social exclusion of disabled children and young people continues because local authorities locate the problem in the disabled child rather than considering external factors such as social, physical and organisational structures that contribute. The social model of disability has been critiqued and further developed. Shakespeare and Watson (2002) argue that the model dichotomises impairment and disability rather than seeing them as different places on a continuum or different aspects of a single experience.

Davis and Watson (2000) state that focusing on the social model downplays the agency of disabled children and young people and treats them as passive victims who require adult support, and whose lives can only be analysed in terms of isolation, access to service provision or the acquisition of material support. Connors and Stalker (2007) attempt to start a dialogue concerning the interplay of the social model of disability and disabled children's lives. Drawing on the work of Thomas and O'Kane (1999), they report on a study of disabled children's experiences of disability, and identify that children experienced disability in four ways in terms of: impairment, difference, other people's reactions and material barriers. Thus when thinking about disabled childhoods they argue that "impairment effects", "barriers to doing" and "barriers to being" all have a place. These debates are important as they shape the ways in which disabled children and young people are viewed and treated, and thus impacts upon the opportunities afforded to them to participate in decision-making.

Typologies of attitudes towards participation

Attitudinal barriers to participation may to some extent exist because this is a relatively new way of working and practitioners may lack the experience, capabilities and skills to facilitate participation. They may not have received any or adequate training and thus may have concerns about their own abilities, particularly expertise in communicating with disabled children and young people with communication needs, and the consequences of participation. There was also until recently a lack of information or forums for exploring good practice. However, the establishment of a small number of resources should help to alleviate some of these problems. See for example, the Participation Workers Network England (PWNE) and Participation Works (www.participationworks.org.uk) (an online gateway for youth participation), and a specific disability focused source of information on disabled children's participation, The Children's Society Disability Toolkit (www.disabilitytoolkit.org.uk).

Thomas and O'Kane (1999) developed a typology of adult attitudes to children's involvement basing it on Mayall's suggestion (1994) that the level of children's participation varies according to how the adults in specific

social settings conceptualise children and childhood. They also identified a number of different attitudes in what adults said or implied about children's involvement in decisions and the reasons for including or excluding them. The four identified approaches were: clinical, bureaucratic, value-based and a cynical approach.

- *Clinical approach* – this focuses on the child as in need of treatment. Discussions about including children in decision-making processes are therefore likely to revolve around their emotional capacity or incapacity and their vulnerability to distress. This often leads in practice to the exclusion of children on the basis that they are "not ready", "would not understand" or might make a "regrettable decision".

- *Bureaucratic approach* – this centres upon fulfilling organizational and procedural requirements in relation to decision-making which may leave little space for effective children's participation. Thomas and O'Kane identified two variations within this. The first was mainly expressed by social workers who said that they would like to involve children more but regrettably bureaucracy prevented this because the procedures were inflexible or because of the demand of their other responsibilities. The other view was expressed by workers involving children who stated that they had involved children more than they had done in the past or more than they would have done because it was now a procedural requirement.

- *Value-based approach* - this regards children's involvement in decisions as positively good, either because it is a child's right or because it leads to better decisions, practice and better outcomes.

- *Cynical approach* – this is characterised by one or more assumptions or assertions; that children have too much to say already, that they do not know what is best for them, that they want power without responsibility or that they are spoiled.

Thomas and O'Kane (1999) also produced a typology of adult attitudes to including disabled children and young people which illustrated a clear distinction between those who focused on the child's capacities or lack of them and those who focused on adult skills or attitudes. They also identified an additional distinction between whether people were positive or negative about the likelihood of children being successfully included.

Figure 5: Matrix of attitudes to participation by disabled children and young people (Thomas and O'Kane, 1999, p384)

	Focus on child	**Focus on adult**
Positive attitudes	*"This child can find ways to make herself understood"*	*"With creativity and determination we can include her"*
Negative	*"Her disabilities are too profound to include her"*	*"I just can't see any way to find out what she thinks"*

There have been few subsequent studies examining adult attitudes to disabled children and young people's participation. However, Franklin and Sloper's (2006, 2007, 2009) research supports the above conclusions. They concluded that although most parents and professionals who took part in their study generally saw the importance of children's participation, there was confusion about what participation should mean or could mean for disabled children, particularly those with communication and/or learning impairments. There were concerns over children's competence, understanding and abilities to participate, coupled with unease about the interpretation of children's views. For some workers there appeared to be a concept of "ideal" participation, based on a notion that anything less than a child taking part in a meeting or contributing to complex decision-making processes was not valid. Some parents/carers also expressed concerns about how their child could be involved but they also questioned the ability of the professional to get their child's view. Franklin and Sloper thus called for a broader understanding of the meaning of participation for disabled children, including the importance of children participating at whatever level is appropriate to their ability, so that children of all abilities participate in decision-making processes. Interestingly, these authors also highlight how parents and professionals reported a change in their attitudes as a result of seeing participation in operation. Their once held beliefs about the impossibility of involving a child due to, for instance, a communication need were challenged and they reflected that they had underestimated the child and the methods being adopted.

A failure to acknowledge the beliefs and assumptions held about children's competence, capabilities and vulnerability is likely to exacerbate the hidden barriers to participation (McNeish, 1999; Matthews, 2001; Kirby and Bryson, 2002). Assuming children and young people are incompetent, irrational or irresponsible will create barriers to their participation, as will assuming that "adults always know best". Davis and Watson (2000) argue that disabled children and young people, whatever their impairment can be competent in every day decision-making processes:

> "*When they are provided with the opportunities to interact with other children on an equitable basis, their participation is properly planned and not reliant on short-term adult assessments of competency and when they are able to work with reflexive adults.*" (p213)

However, they state that competency is denied to many disabled children in day-to-day settings by adults, because often disabled children and young people are seen as different and "not like us", because the children are judged against supposedly objective criteria such as, not being seen as able to achieve set attainment targets and levels, they are seen as not being able to communicate and interact with their peer group and others, they are seen as being unsafe, and a danger to themselves and others.

Other studies have also shown how attitudinal barriers and/or lack of understanding of participation do exist. In Oldfield and Fowler's (2004) mapping exercise of participation, only half of respondents in statutory organisations agreed strongly that senior managers valued the right of

children and young people to be involved and only a third believed they understood the practical implications of participation. Respondents also reported that the top three actions they thought organisations and government should take to promote effective participation were; senior management commitment, long term funding and attitudinal change amongst adults.

Prout (2003) suggests that:

> "...too often children are expected to fit into adult ways of participating when what is needed is institutional and organisational change that encourages and facilitates children's voices." (p32)

Similarly, Willow et al (2004) argue that:

> "It is only when children are recognised as people in their own right that adults can acknowledge that they have their own ways of understanding the world and are capable of defining their own needs, rights, interests and responsibilities. Recognising and respecting children in these ways is the necessary precursor for developing appropriate modes of participation and knowing how and when (and when not) to employ them. Without due recognition and respect, participation may become an empty exercise, a token gesture or a manipulative and exploitative practice." (p9)

Expectations of participating in adult modes of behaviour

It is still often the case that children and young people's inclusion in decision-making processes is conditional on them assuming "adult" modes of behaviour, communicating in adult language or via adult forums, or in forums which mirror adult bureaucratic structures (e.g. school councils, youth forums) which are frequently child-unfriendly in their procedures and culture. Children and young people repeatedly state that venues, timing, procedures and jargon often act as a barrier to their participation. It thus could be argued that participation still appears to be on adult terms. For some supporters of participation, one outcome should be that children and young people set the agenda for participation. Yet evidence repeatedly indicates that when children and young people are consulted they are generally asked about issues of importance to adults. This is perhaps not surprising given the current climate of quality assurance, organisational accountability and limited resources (Thomas and O'Kane, 1999; Willow et al, 2004).

Participation versus protection

One of the challenges facing professionals is that they have to balance the participation rights of young people with their own responsibilities to provide care and protection. The need for such a balance is recognised within both the UNCRC and the 1989 Children Act. Children and young people's right to protection and participation are often viewed as in opposition to each other or mutually exclusive, yet these rights should be seen as interlinked promoting participation in decision-making can enhance

a child's protection. There is widespread acknowledgement that children and young people's safety in the care system relies on them being listened to and involved in decisions both within their own lives and also in general policy (Utting, 1997; Waterhouse, 2000; Laming, 2003).Yet such acknowledgement has not translated into improved practice for disabled children and young people. Disabled children are significantly more vulnerable to abuse than non-disabled children (Marchant and Page, 1993; NSPCC, 2003). Twenty-eight per cent of children and young people in care are disabled and disabled children and young people are eight times more likely to be in care than their non-disabled peers (Loughran et al, 1992 cited in Morris, 1995). These statistics remain largely ignored in the debates concerning the voices of children in care, and it should be noted that some disabled children and young people may require specialist provision and access to professionals with skills in communication methods in order for them to have their views heard. A number of writers emphasize this "double jeopardy" for disabled children living away from home (Marchant and Page, 1993; Westcott, 1993; Morris 1995, 1998b, 1998c). Critics of participation argue that too much decision-making denies children and young people their childhood, turns them into miniature adults and encourages selfishness. Others highlight the potential risks of participation for young people. This might include: imposing responsibilities for which young people have not been prepared; exposing them to peer pressure; involving them in tasks for which they do not have the confidence or skills; involving them in public presentations or media activities where they have not fully understood the possible implications, or involving them in project activities to the exclusion of other interests in their lives. It could be argued that these risks are not inherent in participation itself, but can result from ill conceived or poorly planned processes, for example, when there might be insufficient time and resources provided, and when there is a lack of understanding of children and young people's participation (Willow, 2002).

Lack of choice and fear

Sometimes a lack of choice or the fear that children and young people will make inappropriate choices can act as a barrier to participation. (Willow et al, 2004). Children and young people may be presented with an apparent opportunity to make decisions when their choices are in fact limited or non-existent (Willow et al, 2004). Equally, some professionals might be concerned about involving children and young people and raising their expectations about possible outcomes. Willow et al (2004) argue that this should not be used as an argument for excluding children and young people's voices but that participation should address how decisions are made.

Under estimating disabled young people's abilities

Disabled children and young people, particularly those with learning disabilities, may face an additional barrier in that people may feel that they lack the necessary cognitive abilities to make decisions. In 1996, Lanciono et al, published a review of evidence on choice research with people with complex learning disabilities. They concluded that, when presented in an accessible way, most people with complex learning disabilities can make

choices and express preferences about food, drink items, types of stimulation and activities. They also highlighted the importance of the environment and access to technology to facilitate the expression of choice. Developing the ability to make choices may require practice and may also demand specific skills on the part of professionals and/or family members to understand both an individual's way of communication and the context in which communication behaviour is observed.

However, choice regarding future events, Ware (2004) notes require "*a relatively advanced level of cognitive development*"' and cannot be made by people with severe developmental disabilities. Ware concluded:

> *"This is not to suggest that the lack of trying to ascertain the views of people with profound and multiple learning disabilities should be abandoned. Rather we need to be realistic about the extent to which it is possible to ascertain the views of those with the most complex needs about complex issues. We need on the one hand, to see the task of enabling someone to express their views as a learning/teaching task which may be very long term, and on the other, when major decisions need to be taken about their future, we need to work out how best to take account of their likes, dislikes, strengths and needs."* (2004, p178)

Thus disabled children and young people should not be excluded from decision-making processes and from being given choice, but it should be at an appropriate level for them and continually reassessed to monitor for development. We have already noted that groups of children and young people previously deemed "hard to reach" are now actively taking part in research and consultations, thus notions of ability are fluid and dependent on the methods and approach being adopted.

6.6 Structural barriers to participation

In addition to the above attitudinal barriers and prevailing views about children and young people, there are often very real practical barriers which have to be overcome in order for participation to be successful. Although it should be seen that many of the structural barriers would and could be addressed if there were more positive attitudes toward this way of working with children and young people.

Structural barriers include the:

- complexity and bureaucratic nature of organisations (for example, Matthews, 2001; Kirby and Bryson, 2002; Kirby et al 2003a, 2003b)
- lack of training and support for adult facilitators and young people participating (for example, Kirby and Bryson, 2002; Cavet and Sloper, 2004)
- lack of research evidence to support participatory activities (for example, Dixon-Woods et al, 1999; Hennessy, 1999; The Children's Society, 2007).

Willow et al (2004) reflect on the paradoxical situation which has developed within policy and social care practice. They argue that while the principles of greater involvement of children and young people is at the heart of much governmental legislation and guidance, the pressures created by this guidance can drive practice in the opposite direction. For example, social workers now work within a more structured assessment framework which requires consultation with parents, other adults and considerable quantities of paperwork. As Hill previously noted:

> *"Young people feel their personal needs and wishes are often sidelined as a result of social workers' preoccupation with fulfilling legal and procedural requirements."* (1997, p24)

It appears from the literature that the interplay of structural and attitudinal barriers is still at the heart of disabled children and young people's participation. The Children's Society (2007) concluded that the barriers to disabled children and young people's participation were:

- time constraints mitigating against meaningful communication and relationship building
- availability of specialist staff and training, staff shortages and large caseloads
- difficulties in the relationship between the social workers and young people's family
- societal attitudes towards disabled people
- some professional's belief that disabled young people do not have views or perceive them only as recipients or beneficiaries of services.

Kellet (2010) reports on the barriers to participation in youth forums identified by a group of disabled young researchers. These barriers included when:

- people speak too fast and use complex language and jargon
- minutes of meetings are not sent out in advance and have to be read during the meeting
- minutes and agenda papers with small print and no pictures are hard to read
- timings of meetings are often fixed for straight after school when young people are hungry and tired
- places of meetings are frequently inaccessible.

The young people also identified what was needed to overcome these barriers and the following section highlights the identified facilitators for participation.

7. Research evidence - Factors which appear to support the participation of disabled children and young people in decision making

The following chapter explores the available evidence on factors which help to facilitate the participation of disabled children and young people in decision making. Because of a dearth of studies on disabled children per se, the wider literature on children and young people generally has been examined. All of the evidence points to a few key factors: an "enabling approach", training and resources, flexible and accessible methods and embedding a culture of participation.

Key facilitators to supporting participation

➢ Adopting a positive, can-do attitude and a rights based approach towards participation.
➢ Working within the social model of disability, and addressing the barriers disabled children face to participating such as not having communication or access needs met.
➢ Providing access information to disabled children and young people.
➢ Ensuring the decision making issue is relevant to young people.
➢ Ensuring that the method of participation is interesting, meaningful, flexible and accessible to disabled children.
➢ Ensuring that young people feel valued and respected for their work by providing feedback following their involvement in decision making (even if this is not a positive outcome for them).
➢ Ensuring participation is ethical and adheres to clear principles of good practice.
➢ Providing practitioners and young people with support and training.
➢ Embedding participation within the organisation.

7.1 An "enabling" approach to participation

Disabled children and young people are children first and what excites and engages them is no different from that of their non-disabled peers. As Stalker and Connors (2003) write:

> "Talking to disabled children is often no different from talking to any child, the most important "rule" is probably to see the child as a child first and disabled second." (p27)

Overwhelmingly, the evidence suggests that it is imperative to get the basics correct; a positive attitude to participation, a starting point of "how can I include this child"; a rights based approach, providing accessible information, and addressing any access and communication needs. Of course, this is not to deny that there will be some specific challenges which might need additional consideration. For example, the involvement of children with severe autism poses particular challenges, for a discussion on this see Preece, (2002).

Much can be learnt from the generic literature about supporting and facilitating participation, many guides and articles highlighting pointers for good practice now exists (see for example: Treseder, 1997; Cohen and Emanuel, 1998; Sinclair and Franklin, 2000; McNeish, 1999; Children and Young People's Unit, 2001a; Clark and Moss, 2001; Shier, 2001; Combe, 2002; The Children Society, 2002; Cutler, 2003; Kirby et al, 2003a; Badham and Wade, 2005, 2010;Participation Works, 2008a).

Some guides highlight the advantages and disadvantages of certain methods, however, there is still limited guidance for services wishing to develop the participation of disabled children and young people, particularly concerning children with more complex needs, and how any additional barriers they might face can be overcome (see for example: Action for Children, 2006; Council for Disabled Children and Participation Works, 2008; Dickens 2004; Making Ourselves Heard, 2009; Kirkbride, 1999; Lightfoot and Sloper, 2002a; Marchant and Jones, 2003; Morris 1998b, 2002; Martin, 2008; Royal College of Paediatrics and Child Health, 2010; Stalker and Connors, 2003, Ward, 1997; Watson et al, 2007; Wright et al, 2006).

Despite the increasing plethora of guides, it is not always clear where the evidence for this advice on good practice has come from. In most cases, evidence is gathered from adult facilitators of participation activity; there is relatively little evidence from children about their experiences of involvement, although some data are now emerging (Matthews, 2001; Combe, 2002; Lightfoot and Sloper, 2002b, 2003; Kirby et al, 2003b; Kellet, 2010).

McNeish and Newman (2002) highlight a number of factors considered important in motivating young people's involvement:

- The issue needs to be important and relevant to young people.

- The activities need to be fun and interesting.

- Young people need to get some personal benefit from being involved such as personal satisfaction.

- Incentives and rewards are important.

- Young people need to feel valued and respected, and that their views are being listened to.

- Evidence of results, seeing the results for their efforts and hard work. This can be difficult if projects are working towards longer-term objectives, it is thus important in this case to build in some tangible results at the earlier stages.

- Young people need to be given feedback about what will happen and how their work will be used. Franklin and Sloper (2006,2007, 2009)

found few examples of children being given feedback on what was happening as a result of their participation.

Willow et al (2004) consider the core principles that professionals need to involve children and young people. They define these as:

- demonstrating respect, interest and care
- attempt to see the world from the child's perspective
- use clear and appropriate language
- listen and observe the different ways in which children communicate their feelings and preferences both verbally and non-verbally.

Similar principles have been identified within specific reports on disabled children. Knight et al's (2006) review of consultations undertaken with children and young people with learning disabilities about the support they receive illustrated that the over-riding issues identified by the children and young people included; the importance of a trusted adult who communicates directly with them and choice, both in day-to-day matters and in more major decisions such as at times of transition. The review concluded that consultations needed to take into consideration the importance of gaining knowledge and competence in the young person's preferred ways of communicating and clarifying the purpose of any consultation to ensure it will be of benefit to young people including those directly involved (Knight et al, 2006).

The Royal College of Paediatrics and Child Health (2010) developed a set of principles and values for clinicians and service providers to engage children in developing health services. These consist of ethical issues, honesty and transparency, health and safety, confidentiality, consent, safeguarding, a positive environment, issues of communication, and equality and diversity.

All of the above, highlight that integral to participation is the preparation, information and support given to children and young people to enable them to develop their understanding of participation and capacity to become involved. However as already noted, disabled children and young people face additional barriers to participation and there is less published evidence on how to overcome these and further promote disabled children's participation. Morris (2003) provides an account on how to include all children, including those with communication needs and/or cognitive impairments. Here she draws upon the learning from four projects, and concludes that the following are vitally important when facilitating the involvement of these groups of children and young people:

- Each individual child has to have their access needs met through asking them what help they may require in order to participate and offer to organise transport, personal assistance and communication facilitation.

- Information provided to participants is fully accessible and provided in their preferred communication method. Information should explain that any cost incurred will be reimbursed.

Watson et al (2006) drawing on their own experiences of undertaking research highlight pointers for best practice when trying to find out about the experiences of disabled children and young people. These include; assuming everyone can communicate, recognising the barriers that will be put in your way (for example, adults telling you that a child cannot communicate); flexibility when seeing the child and attending at a time suitable for them; having resources to hand like paper, pens, toys, pictures etc but be prepared not to use them if they do not work or feel inappropriate and do not feel bad about making mistakes or not understanding when someone is trying to tell you something – persevere. Morris (2002) provides a checklist for social workers and others consulting with disabled young people with communication impairments. Whilst Lewis et al (2005) discusses a wide range of approaches to eliciting the views of children and young people with special educational needs, including the strengths and weaknesses of methods such as interviews, drama and rankling exercises, puppets, drawing, cue cards and photographs.

Overall the evidence suggests that for participation to be effective the methods of involvement should be appropriate to the needs of disabled children and young people and those facilitating participation, and that no one approach is necessarily deemed to be the right one rather flexibility should be the overall goal (Beresford, 1997; Ward, 1997; Morris, 1998a; Russell, 1998; Marchant et al, 1999a, 1999b, Morris, 2002; The Children's Society, 2001a; Lewis et al, 2005; Watson et al, 2006).

Many disabled children want informal, on-going approaches to facilitate their involvement, in addition to formal structures and isolated events (Lightfoot and Sloper, 2003). Authors highlight the importance of creative, multi-media methods and flexible approaches (Ward, 1997; Marchant et al, 1999a; 1999b; Morris, 2002). However, few studies have systematically examined or assessed the impact or outcomes from such approaches.

Some specific methods to facilitate participation are highlighted within the evidence base. Talking Mats™ is a pictorial framework that has been used as a tool for young people with learning difficulties and/or communication needs to express their views. Talking Mats™ uses picture symbols which represent topics, options and emotions. Young people place the pictures showing the possible options under appropriate emotion symbols to express their feelings. The completed mat can be photographed and kept as a record of the participant's views and wishes around a certain topic (Cameron and Murphy, 2002; Germain, 2004; Rabiee et al, 2005a). This method has been used in a number of contexts: for example, transitions (Cameron and Murphy, 2002), out of school activities (Germain, 2004), in defining outcomes (Rabiee et al, 2005b) and in mental health assessments (Macleman, 2010).

The Mosaic Approach has also been successfully used to facilitate the involvement of young children. The approach has been subsequently adapted for use with children and young people with autistic spectrum disorders in research to establish their views about the outcomes they wished to gain from social care and support services (Beresford et al,

2004). This is a multi-method approach originally developed to enable young children under five years old to express their views (Clark and Moss, 2001; Clark, 2004; Clark and Statham, 2005). It brings together a range of visual and verbal methods to enable children to take an active role in expressing their views, forging traditional tools such as observation and interviewing and triangulating them with methods harnessing children's creativity and physical engagement with their world using tools such as cameras, tours and map making of the child's environment.

Knight et al (2006) comment on the use of facilitated communication. This is an alternative communication technique which relies on the role of a facilitator who places their hand over the hand of the child and supports their hand, arm or wrist above a keyboard or board displaying words, letters or images. The intention is to assist the child in the physical act of making a selection without influencing the selection. This method of communication has attracted controversy because of the difficulty in establishing if the child is being supported or led into making a choice. However, as Knight et al conclude, despite the divided opinion over the method, it may enable children to express their views in which otherwise they would not be included (for example, Connors and Stalker, 2003). Similar in Knight et al's paper they report on the *In my shoes* computer package which was developed to help children communicate about aspects of their life, including around safeguarding issues (www.inmyshoes.org.uk). Non-instructed advocacy, as already discussed is another potential mechanism to facilitate involvement in decision making.
However, little information has been gathered on the use of these resources and whether use of these techniques is widespread in practice, and little information has been collated with regard to the outcomes of their use.

There are some common themes which can be derived from across the literature which are identified as being important to the success of participatory work with children and young people.

7.2 Clarity and shared understanding

Clarity on the purpose, objectives, parameters and possible outcomes of participation is fundamental (Children's Taskforce, Department of Health, 2001; Sinclair and Franklin, 2000; Kirby and Bryson, 2002; Franklin and Sloper 2006, 2007, 2009). Sinclair (2004) states that only when the purpose of participation is clear can adults be honest with themselves and with children involved. Lack of clarity can also lead to tokenism and misunderstanding about the level of involvement children may have and make it difficult to evidence change as a result of participation (Willow, 2002). When children are approached to participate they need clear accessible information about what participation will entail, what it will hopefully achieve, and arrangements regarding confidentiality, anonymity and the option to opt out (Alderson, 1995; Sinclair and Franklin, 2000; Lightfoot and Sloper, 2002a, 2003).

7.3 Staff training and development

There is a recognised need for staff training and skills development in order to promote participation (for example, Hennessy, 1999; McNeish et al, 2000; Children's Taskforce, Department of Health, 2001; Kirby and Bryson, 2002; McNeish and Newman, 2002; Lightfoot and Sloper, 2002b, 2003; Kilgour, 2002, Oldfield and Fowler, 2004; Franklin and Sloper 2006, 2007, 2009).

Willow et al (2004) argue that alongside specialist training in, for example, communication skills - there should be training in the ethos of children's citizenship, and that such training should be given not only to frontline staff but also managers, inspection staff and policymakers. Other commentators have expressed similarly that training and development programmes need to address attitudinal changes in professionals about childhood and adolescence, particularly concerning consent and competence (Alderson and Montgomery, 1996); about communication including training in methods of communication with children who do not use speech (Beresford and Sloper, 1999; Franklin and Sloper 2006, 2007, 2009). Similarly, Franklin and Sloper highlight the need for training in creative methods and IT, and training in theory and methods of participation with particular reference to children with communication needs and learning disabilities.

Willow et al (2004) also highlight the skills required to analyse children and young people's views, avoid adult interpretation and present children and young people's views in ways understandable to the target audience, thus avoid misrepresentation of children and young people.

7.4 Training, support and development for children and young people

Young people may also need support and training to increase their confidence and self-esteem, or may need skills development in, for example, group work or giving presentations (Treseder, 1997;Cohen and Emanuel, 1998; Combe, 2002; Kirby and Bryson, 2002; Kirby et al, 2003b). Franklin and Sloper (2009) note that preparing disabled children to express their views can take time and may need an individual approach. They also highlight that there needs to be a recognition that supporting children to participate is time consuming; it requires getting to know a child, understand their communication and prepare them to express their views. Young people may also need very practical support such as transport, information about the organisation's decision-making processes, assistance with communication, personal assistance or accessible venues (2007, 2009).

7.5 Using flexible and appropriate methods

There are a number of publications that highlight the advantages and disadvantages of numerous methods of involvement and emphasise that flexibility and the use of a wide range of methods and approaches is important (for example, see Cohen and Emmanuel, 1998; Kirby and Bryson, 2002; Lightfoot and Sloper, 2002a, 2003). The necessity of

tailoring methods to be appropriate for children cannot be underestimated, taking into account factors such as their age, ethnicity, gender, individual circumstances and support needs. Cavet and Sloper (2004) summarize the evidence surrounding inclusive approaches to involving disabled children and young people. They highlighted from the available evidence the following as important:

- using a multi-media approach or variety of methods
- availability of resources such as communication aids or interpreters
- use of advocates or mentors and multiple contacts in order to get to know the young person
- flexibility about how children participate and recognising that children communicate in mediums other then speaking
- independent facilitators so that children can give their views about services they use in confidence
- the need to make participation fun and rewarding.

Settings need to be accessible, comfortable, private and appropriate to a young person's culture. Many children find the unusual style of meetings uncomfortable. If meetings are to be used, issues need to be considered such as timing, location and how they are conducted. McNeish and Newman (2002) suggest that participants should be given the opportunity to get to know each other so that they feel comfortable and confident. Young people should have the opportunity to influence the agenda and have adequate support and information. Of equal importance is having sufficient numbers of young people present so they are not outnumbered and intimidated by adults.

7.6 Embedding practice

> *"It's a bit like we get involved for a week or a month but then it peters out until the next time they want us"*
> (Young Disabled Person, quoted in Franklin and Sloper (2006)).

Sinclair (2004) argues that if children and young people's participation in decision-making is to be more meaningful to children and effective in influencing change, it is necessary to move beyond one-off or isolated participation and consider how participation becomes embedded as an integral part of our relationship with children. Consideration is needed to ensure that participation is more effective in the impact it has on decisions and on decision-making processes and ultimately on participation structures and cultures.

For advocates of participation the objective is to reach the position where participation is not seen just as a desirable add-on but something that is firmly embedded. Kirby et al (2003b) draw on research from 29 case studies which indicate how organisations can develop the role of participation within their organisation and move from being consultation–focused to participation-focused to child-focused. This study highlights ways in which organisations can start to build cultures of participation through organisations making changes in attitude, procedures and styles of working across all levels, create champions of participation to support change across

the whole organisation, and develop a shared vision and understanding of participation. The authors identify that the key to this is senior management support and a mainstreaming of practice. Similarly, Oldfield and Fowler (2004) argue that participation requires genuine commitment across all levels of the organisation and requires "buy-in" across elected or board members, senior and middle management and practitioners. They also advocate "participation champions" who at least in the short term can offer support and help to promote participation. Likewise encouraging workers to "give participation a go" may help persuade them to value the voices of children and young people. Organisations need to develop learning processes and allow professionals to learn, try and reflect on practice. Hear by Right also challenges organisations to achieve this objective of mainstreaming participation, by questioning their current structures and cultures (Badham and Wade, 2005, 2010). Hear by Right offers a framework for organisations across the voluntary and statutory sectors to self-assess their participation and improve practice and policy on the participation of children and young people.

It is recognised that the culture, structures and systems of organisations impact on participation activity (Kirby and Bryson, 2002; McNeish and Newman, 2002; Kirby et al, 2003a, 2003b; Cavet and Sloper, 2004). A listening culture among staff is essential as well as genuine commitment, so that young people feel respected and confident to express their views, and have their views listened to and responded to (McNeish et al, 2000; Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; McNeish and Newman, 2002; Lightfoot and Sloper, 2003). However, the evidence suggests that this is some way off, Franklin and Sloper's (2006, 2007, 2009) study illustrated that disabled children's participation was very fragile and often rested on a few specific individuals with a passion. It was susceptible to staff turnover and sickness, and key staff having a much wider remit, so that other activities often took precedence over participation. Activities also appeared to be taking place in isolation. In addition, they also note the difficulties, expressed by workers, in trying to move from ad hoc activities to embedded practice. They quote one manager who expressed that it required a whole culture change, whereby disabled children's participation and communication with children, by whatever means suits each child, was an expectation. Yet, they also reported that where appropriate tools are developed, workers were given the time and confidence to use the tools and senior management championed the process and monitored practice, participation was achieved, even for those groups who are often deemed "hard to reach".

7.7 Resources

Effective participation involves a considerable amount of planning and preparation and may not be fruitful in terms of immediate successes; setting realistic timescales is imperative. Resources are required to provide training, support and skills development as well as to provide specific practical costs such as transport, resources and equipment for groups and also to ensure that young people are compensated for their time and contribution. Effective participation can be extremely labour and time intensive (Fitzpatrick et al, 2000; Oldfield and Fowler, 2004). Participation

work requires time for adults and children to form relationships, and get to know and trust each other. Willow (2002) notes that this is particularly pertinent when considering the participation of children and young people with communication needs. Little evidence has been collated on the cost of participatory activities or indeed, on the cost-effectiveness of different models and processes of participation (Cavet and Sloper, 2004).

7.8 Ethical standards, key principles and values

Most of the debate about ethics tends to focus on children and young people's participation in research or on consent issues (such as consent to medical treatment) and appropriate guidelines have been produced (Alderson, 1995; Morrow and Richards, 1996; Alderson and Morrow, 2004). Yet there are important ethical considerations to be taken into account when children and young people are participating (Ward, 1997). These include making sure that participation will not result in any harm to any young person, being able to justify an exclusion of young people; ensuring that participation has been without coercion or pressure, ensuring that young people fully understand what they are involved in and the role expected of them and ensuring that young people have the opportunity to opt out of participation at any stage.

Whatever the nature of the participation activity it is important that those involved ensure their practice reaches appropriate ethical standards. But there are few standards of participation published, although this is increasing rapidly (for example, Save the Children, 2005 and The Royal College of Paediatrics and Child Health, 2010; also see examples on www.participationworks.org.uk). Ethical and practice standards are being developed partly in recognition of the different power relations that exist between practitioners and participants. It has been argued that as children are particularly vulnerable and lacking in power that explicit standards or ethical statements of practice are needed to take account of this imbalance. We must also not forget that participation is a choice and that some children and young people might not want to participate and might choose to withdraw from the process, remain silent or provide a non-response. This is also their right. However children are particularly susceptible to intrusions of private space so the urge to hear children's views must be balanced with respect for their choice to not participate (Lewis, 2004, Alderson and Morrow, 2004; Christensen and James, 2000).

8. Research evidence: What are the impacts/outcomes from the participation of disabled children and young people in decision making?

The following short chapter reflects the lack of available evidence on the impacts and outcomes of disabled children and young people's participation. There is a lack of evaluation of practice and limited monitoring of whether involvement is impacting on policy, practice and resource decisions. However, the small amount of evidence available does illustrate that when disabled children and young people's participation is undertaken properly it can lead to positive change.

Key findings

➢ There is a lack of evaluation of disabled children and young people's participation both in terms of process and outcomes.
➢ There is a severe lack of systematic evidence that the participation of disabled children and young people is having a major effect on policy, practice and resource decisions.
➢ The limited available evidence illustrates that participation can lead to better services and the personal development of the young people participating. In addition, it can lead to increased practical and communication skills amongst practitioners.
➢ From the available evidence of disabled children's participation, when it is conducted well, it can lead to very positive change.

Despite a growth in participation, there is a lack of evaluation in terms of processes and outcomes (Kirby and Bryson, 2002; Cavet and Sloper, 2004; Sinclair, 2004; Badham, 2004). Davey's (2010) survey of organisations showed only 37% evaluated the impact of participation on their organisation.

For many, children and young people's participation is a rights based principle and not something that has to be justified by evidence. However, as Sinclair (2004) states this should not diminish the need for monitoring or evaluation as part of a learning culture, so that more can be learnt about making the process meaningful and bringing about sustainable change.

However, unless evaluation is built into individual projects (and resourced) then practitioners will not be able to reflect on and improve their practice. Oldfield and Fowler (2004) who mapped children and young people's participation in England found that the use of monitoring and formal evaluation procedures was limited in both statutory and voluntary organisations. Fewer than two-fifths reported that their organisation carried out formal evaluation. Yet simple systems such as asking children and young people to directly comment on the process is easy to facilitate and can elicit extremely useful feedback. Likewise on a strategic and national

level unless information is collated on initiatives across a range of services and contexts then shared learning and improvements in practice will be limited. Oldfield and Fowler (2004) report that in their mapping of participation in England, fewer than half of respondents agreed strongly that participation was integral to their organisations work or that services had improved as a result of involving children and young people.

There are only a few systematic evaluations of the process of participation (Combe, 2002) and even fewer studies that address the outcomes of participation, whether for children, adults, services or organisations (Kirby and Bryson, 2002). Current evidence can tell us a little about what seems to work best in the process of engaging children and young people in decision-making, it can tell us virtually nothing about whether the outcomes for children are better as a result of their engagement. Research evidence has to date been largely exploratory and descriptive, providing account of different approaches to participation and their perceived advantages and disadvantages from the view point of the adult facilitators. This area now needs to be developed further with more evidence collated on benefits to the individuals participating and the wider constituency of children and young people. Outcomes need to be considered in terms of not just changes to services, but also the impact, effect or consequences of participation on an individual level for those young people participating, and in turn at the population level of those children and young people accessing the services which may have developed or changed as a result of participation. Many of the recently produced guides to participation contain case studies illustrating outcomes from individual projects (see for example; Participation Works, 2008a; Making Ourselves Heard, 2009; The Royal College of Paediatrics and Child Health, 2010), whilst this is a positive step forward, there still remains a gap in terms of systematic evidence of change, and from these small number of examples, it is hard to judge why in these cases change occurred when it appears not to have in so many other situations.

One of the challenges with measuring the impact of participation lies in the fact that often participation activity is funded only in the short-term and it can be difficult to track the process of decision-making and implementation over the longer term. In most cases, monitoring systems are not put in place to track activities and, for example, how young people on strategic decision-making panels are influencing decisions. Franklin and Sloper (2006, 2007, 2009), in their study of decision-making in social care, followed a number of case studies for nearly two years and found limited evidence of measurable outcomes. None of these case studies had systematic procedures for recording, monitoring or evaluating the activities undertaken. However, what they could conclude in this study was that where participation did happen, all children, parents/carers and social care staff reported positive effects including children feeling included, valued and listened to, they gained confidence and new skills and enjoyed the attention and having fun. A number of useful guides to evaluating participation work have been published, including Kirby and Bryson (2002) or Participation Works (2008b).

From the limited literature available the perceived outcomes of participation include: better services, personal development of young people, and enhanced citizenship and social inclusion (see for example: Kirby et al, 2003b; Davey et al, 2011). Improved service accessibility is identified through the use of more suitable venues, opening times, and accessible information. Other benefits include improved relations between adults and children; increased practical and communication skills for staff and increased confidence and increased compliance to medical treatment and take up of services among young people (Kirby et al 2003b; Lightfoot and Sloper, 2005). Franklin and Sloper (2006) from their survey of social care services reported that 31 out of 70 initiatives indicted changes to services as a result of disabled children and young people's participation – most changes were reported to be altering activities or changes to décor, for a small number improvements were made in information provision for disabled children and young people.

Lightfoot and Sloper (2003) identified changes in health services as a result of disabled young people's participation. These included changes to the hospital environment including ward décor and recreational facilities, food and clinic times, ward routines and improved information provision. The participation process was said to have increased social contact and peer support for young people and had led directly to the opening of a youth club for young people with Autistic Spectrum Disorders. Interestingly they also report that participation had led to changes in commissioning, prioritisation of planning, and a commitment to include disabled children and young people in decisions. However, 13 out of the 27 initiatives which were identified reported no changes to service provision citing reasons such as lack of resources or the length of time the decision-making process takes.

However, there is little evidence that participation is having an impact on major polices and resource decisions. It is still the case that more is known about how to support young people to make participation more rewarding for them, but less about how participation can bring about change. Within this emerging literature, the reported outcomes of disabled children and young people's participation remains very limited. There was also little commitment from the previous New Labour government to systematically evaluate the outcomes or processes of participation despite empowerment being a major element of their policy.

It is still the case that very little information has been gathered from disabled children and young people about their own experiences of participation. However, when asked they report it to be a very positive experience (Franklin and Sloper 2006, 2007, 2009). Children want to be able to evaluate their participation in decision-making so they can identify if they have had an impact or understand the reason behind why certain decisions have been made (Davey, 2010). Davey reports on how children who do not receive feedback on their participation feel disillusioned with power-sharing, belittled, powerless and undervalued.

6. Conclusion

This literature review set out to examine existing evidence concerning the participation of disabled children and young people in decisions about services – collective decision making. Because of the severe lack of evidence in this area, the wider literature on the participation of children has been examined and reference made to the growing body of research being undertaking with disabled children. This research sheds light on their views about services and illustrates the capabilities of disabled children to be commentators on their own lives. The growing academic literature and emerging practice are a major step forward in giving disabled children and young people a "voice", but some may argue that this is not really giving disabled children and young people full empowerment and a stake in decision-making processes.

Extent of disabled children and young people's participation

There is a dire need for more research in this area in order to be able to fully answer the questions posed by this project. Firstly, it is difficult to comprehensively conclude where participation is occurring/has occurred and any subsequent gaps. There have only been a couple of studies examining the extent and nature of disabled children's participation across England; one in social care and one in health services both are now dated and they can only provide a snapshot. Looking across the evidence it appears that there has been growth in areas such as youth forums in local authorities but we know, for example, little about how many exist, what decisions they are influencing and what impact they are having. The one area where there is more systematic evidence concerns the involvement of disabled children and young people in the development of short break services. Here there appears to have been an explosion of activity due to the influx of ring-fenced funding under Aiming High for Disabled Children. There is also evaluative evidence illustrating the positive impact this has had on the development of appropriate services. However, this practice must be seen at risk following the removal of ring fencing of this funding.

There is little evidence to suggest that the participation of disabled young people in other services such as health, education or transport is widespread, and indeed the evidence indicates that participation opportunities per se for disabled children and young people are not common. There is no evidence to suggest that there are across the board opportunities for young disabled people to have a genuine influence on decision-making across the full range of services. The available evidence also did not provide any examples of truly embedded participation practice. The examples gathered here often took place in the context of a discrete project, rather than as a holistic way of working which permeated the whole organisation. This has many implications, not least that participation could be seen as one person's job (that of the participation worker) rather than everybody's responsibility to listen to the views of disabled young people.

There is also a dearth of evidence around whether disabled young people are included in mainstream participation opportunities or consultations, alongside their non-disabled peers. Anecdotal evidence suggests that there

are few opportunities for this and that much mainstream participation is not inclusive, however, there is no systematic evidence as yet to establish the true extent of this.

On top of this, all the evidence suggests that only small numbers of disabled young people are participating in decisions about services. Of the examples identified in the review, many were of youth forums or small projects often involving fewer than a dozen, very selective disabled young people. Although, this is not an entirely negative finding (small numbers are possibly better than none, and smaller groups may be better able to meet individual needs), it does raise questions about how representative participants are and how well they can express the views of a wider group of disabled young people.

Negative attitudes towards the participation of disabled children and young people

The evidence gathered also suggests that there still remain negative attitudes towards disabled children's participation. These include low aspirations for disabled children, and/or professionals and practitioners involved in the lives of disabled young people making judgements about the capacity of this group of young people to participate in decision-making. The evidence also illustrates that parents and carers can put up barriers to young disabled people's participation. In addition, it also appears to still be the case that sometimes parents were consulted instead of young people - even though research evidence shows that parents and their children often have very different views. In both cases, young people are not only being denied their rights but are potentially infantilised.

Methods of participation

With regard to examining the processes being used to facilitate disabled children's participation, it can be seen from the evidence that what appears to work well is flexibility, creativity and multiple methods. However, from the evidence we have available it seems that participation processes are often operating in a narrowly focused way, in the main youth forums. We do have more evidence about what works well in terms of facilitating participation, however, this evidence is based in the main on adult perceptions, rather than on systematic evaluations or indeed on the views of disabled children themselves.

Outcomes of participation

Although very limited, the evidence does highlight that participation can have many positive outcomes. More often than not, the evidence refers to the positive effect participation can have on the individual child participating, but also more widely on services and policies. Sinclair wrote in 2004, regarding participation:

> "The first important step was to win the case for children's participation and to see more and more young people being given the opportunity to influence decisions. The second was to make that

involvement more meaningful for children, the next steps are to ensure that participation is more effective in the impact it has on decisions and on decision-making processes and ultimately on participation structures and cultures." (p114)

This still describes the current situation some eight years later. Reports have documented the rights of disabled children and young people and have offered practical steps for participation and information provision. However, much is left to learn about who is involved, where they are being involved, how they are being involved and the outcomes of their involvement.

Need for further research

The lack of research in this area across the board leaves many questions unanswered. Research is also needed to explore the extent, variability and equitability of involvement in decision-making strategic forums, particularly whether disabled young people are represented within mainstream activities, and whether their presence on forums is leading to actual change. The small amount of evidence is also becoming very dated, and the two major studies examining the breadth and depth of disabled children and young people's participation in health services (Lightfoot and Sloper, 2002) and social care services (Franklin and Sloper, 2006) were published over ten years and six years ago respectively. Given the current financial climate there is a real need for evidence on how budgetary cuts are impacting on participation practice, and indeed whether disabled children and young people are being consulted when decisions are being made about service cuts. The lack of evidence concerning cost-effectiveness of different models versus outcomes for services and other young people may also impede upon development and sustainability of practice. It is hoped that this research project will help to support the development of a stronger evidence base to support the participation of disabled children and young people.

Appendix A: Bibliography

Abbott D, et al (2000) Disabled children and residential schools: A study of local authority policy and practice. Bristol, Norah Fry Research Centre.

Abbott D and Carpenter J (2009) Becoming an adult: Transition for young men with Duchene Muscular Dystrophy (DMD). London. Department of Health.

Action for Sick Children (2006) Principles of involving children and young people in the service planning and delivery processes for hospital services. London. Action for Sick Children.

Aires A and Kettle J (1998) When things go wrong: young people's experiences of getting access to the complaints procedure. London, National Institute for Social Work.

Alderson P (1993) Children's consent to surgery. Buckingham, Open University Press.

Alderson P (1995) Children, ethics and social research. Barkingside, Barnardo's.

Alderson P (2000) Young children's rights: exploring beliefs, principles and practice. London**:** 160pp.

Alderson P (2001) Research by children. International Journal of Social Research Methodology **4**(2): pp139-153.

Alderson, P (2002) Young children's health care rights. In Franklin, B (ed) The new handbook of children's rights. London, Routledge Falmer.

Alderson P and Montgomery J (1996) Health care choices: making decisions with children. London, Institute for Public Policy Research.

Alderson P and Morrow V (2004) Ethics, social research and consulting with children and young people. Barkingside, Barnardo's.

Aldgate J and Statham J (2001) The Children Act now: messages from research. London, The Stationery Office.

Arnstein S (1969) Eight rungs on the ladder of citizen participation. Journal of American Institute of Planners **35**(4): pp216-224.

Atkinson, M (ed) (2008) Analysis of Children and Young People's Plans 2007. Slough, NFER.

Badham B (2004) Participation - for a change: disabled young people lead the way. Children & Society **18**(2): pp143-154.

Badham B and Wade H (2005) Hear by right: standards for the active involvement of children and young people, revised edition. Leicester, National Youth Agency and Local Government Association.

Badham B and Wade H (2010) Hear by Right: Standards framework for the participation of children and young people. Revised edition. Leicester. National Youth Agency.

Battrick C and Glasper EA (2004) The views of children and their families on being in hospital. British Journal of Nursing, **(13)**, pp328-336.

Beresford B (1997) Personal accounts involving disabled children in research. London, The Stationery Office.

Beresford B (2002) Preventing the social exclusion of disabled children in What Works for Children? edited by McNeish D, Newman T and Roberts H. Birmingham, The Open University Press**.**

Beresford, B (2004) On the road to nowhere? Young disabled people and transition. Child: Care, Health and Development, **30**, 6, pp581-587.

Beresford B and Sloper P (1999) The information needs of chronically ill or physically disabled children and adolescents. York, University of York, Social Policy Research Unit.

Beresford B et al (2004) Developing an approach to involving children with autistic spectrum disorders in a social care research project. British Journal of Learning Disabilities **32**(4): pp180-185.

Beresford et al (2007) Desired outcomes for children and adolescents with autistic spectrum disorders. Children and Society, Vol 21, 1, pp 4-16.

Beresford B et al (2008) An evaluation of specialist mental health services for Deaf children and young people. York, Social Policy Research Unit, University of York.

Beresford B and Clarke S (2009) Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities. London, Centre for Excellence and Outcomes in Children and Young People's Services (C4EO).

Bignall, T and Butt, J (2000) Between ambition and achievement: Young black disabled people's views and experiences of independence and independent living. Bristol, Joseph Rowntree Foundation.

Boyden J and Ennew J (1997) Children in focus: a manual for participatory research with children. Stockholm, Radda Barnen.

Bradding A and Hortsman M (1999) Using the write and draw technique with children. European Journal of Oncology Nursing **3**(3): pp170-175.

Burke, T (2010) Anyone listening? Evidence of children and young people's participation in England. National Children's Bureau, London.

Cameron L and Murphy J (2002) Enabling young people with a learning disability to make choices at a time of transition. British Journal of Learning Disabilities **30**(3): pp105-112.

Carney T et al (2003) Children's views of hospitalisation: An exploratory study of data collection. Journal of Child Health Care, **7**, (1), pp27-40

Cashmore J (2002) Promoting the participation of children and young people in care. Child Abuse & Neglect **26**(8): pp837-847.

Cavet, J (2000) Children and young people with a hidden disability. An examination of the social work role. British Journal of Social Work, **30**, 5, pp619-634.

Cavet J and Sloper P (2004) Participation of disabled children in individual decisions about their lives and in public decisions about service development. Children & Society **18**(4): pp278-290.

Children's Taskforce and Department of Health (2001) Principles for participation of children, young people and families in the Children's Taskforce. London, Department of Health.

Children and Young People's Unit (2001a) Learning to listen: core principle for the involvement of young people. London, Department for Education and Skills.

Children and Young People's Unit (2001b) Children's fund guidance. London, Department for Education and Skills.

Christensen P and James A (2000) Research with children: perspectives and practices. London, Falmer Press.

Clark A (2004) The Mosaic Approach and research with young children in The reality of research with children and young people edited by Lewis V, Kellett M, Robinson C, Fraser S and Ding S. London, SAGE**:** pp142-156.

Clark A and Moss P (2001) Listening to young children: the Mosaic Approach. London, National Children's Bureau.

Clark A and Statham J (2005) Listening to young children. Experts in their own lives. Adoption and Fostering **29**(1): pp45-56.

Clarke, S et al (2011) Multiagency transition services: Greater collaboration needed to meet the priorities of young people with complex needs as they move into adulthood. Journal of Integrated Care, **19**, 5, pp30-40.

Coad J and Houston R (2006) Voices of children and young people. Involving children and young people in the decision-making processes of

health care services. A review of the literature. London. Action for Sick Children.

Cockburn T (2005) Children's participation in social policy: inclusion, chimera or authenticity? Social Policy and Society **4**(2): pp109-119.

Cohen J and Emanuel J (1998) Positive participation: consulting and involving young people in health-related work: a planning and training resource. London, Health Education Authority.

Combe V (2002) Up for it: getting young people involved in local government. Leicester, National Youth Agency.

Commission for Social Care Inspection (2007) Growing up matters. Better transition planning for young people with complex needs. London Commission for Social Care Inspection.

Connors C and Stalker K (2007) Children's experiences of disability: pointers to a social model of childhood disability. Disability & Society **22**(1): pp19-33.

Cope C (2003) Fulfilling lives: inspection of social care services for people with learning disabilities. London, Department of Health.

Council for Disabled Children (2000) Quality protects: second analysis of management action plans with reference to disabled children and families. London, Department of Health.

Council for Disabled Children and Participation Works (2008) Top tips for participation: What disabled young people want. National Children's Bureau, London.

Coyne, I (2006) Consultation with children in hospital. Journal of Clinical Nursing, **15**, (1), pp61-71

Cutler D (2003) Standard! Organisational standards and young people's participation in public decision making. London, Carnegie Young People's Initiative.

Cutler D and Frost R (2001) Taking the initiative: promoting young people's involvement in public decision making in the UK. London, Carnegie Young People Initiative.

Danso C, et al (2003) The involvement of children and young people in promoting change and enhancing the quality of social care. London, National Children's Bureau.

Davis J and Watson N (2000) Disabled children's rights in everyday life: problematising notions of competency and promoting self-empowerment. International Journal of Children's Rights **8**(3): pp211-228.

Davis J, et al (2005) Reconstructing disability, childhood and social policy in the UK. Child welfare and social policy: an essential reader. Hendrick H. Bristol, The Policy Press.

Davy, C. (2010) Children's participation in decision-making. Report on progress made up to 2010. Participation Works. London.

Davy, C. et al (2011) Youth4U Young Inspectors: Final Evaluation Report. National Children's Bureau. London.

Dean J (2003) Unaddressed: the housing aspirations of young disabled people in Scotland. York, Joseph Rowntree Foundation.

Dee L and Bryers R (2003) Facilitating transitions for people with profound and complex learning difficulties. Journal of Integrated Care **11**(3): pp34-38.

Department for Education (2012) Support and Aspirations: A new approach to Special Educational Needs and Disability Green Paper. Department for Education, London.

Department for Education (2012) Support and Aspirations: A new approach to Special Educational Needs and Disability. Next Steps. Department for Education, London.

Department for Education and Skills (2003) Every Child Matters: presented to Parliament by the Chief Secretary to the Treasury by command of Her Majesty, September 2003. London, Department for Education and Skills**.**

Department of Health (1991) The Children Act 1989 guidance and regulations: volume 6 children with disabilities. London, Department of Health.

Department of Health (1999a) The Government's objectives for children's social services (Quality Protects). London, Department of Health.

Department of Health (1999b) Patient and public involvement in the new NHS. London, Department of Health.

Department of Health (2001) Seeking consent: working with children. London, Department of Health.

Department of Health (2001) Valuing people: a new strategy for learning disability for the 21st century. London, Department of Health.

Department of Health (2002) Listening, hearing and responding: Department of Health action plan - core principles for the involvement of children and young people. London, Department of Health.

Department of Health (2003a) Building on the best: choice, responsiveness and equity in the NHS. Norwich, Department of Health.

Department of Health (2003b) Getting the right start: the national service framework for children, young people and maternity services - emerging findings. London, Department of Health.

Department of Health (2003c) Getting the right start: the national service framework for children, young people and maternity services: standard for hospital services. London, Department of Health.

Department of Health (2003d) Listening, hearing and responding. Department of Health action plan 2003/4. London, Department of Health.

Department of Health (2006) You're welcome Quality Criteria: Making health services young people friendly. London. Department of Health

Department of Health (2009) Valuing people now: a new three-year strategy for people with learning disabilities - executive summary. London, Department of Health.

Department of Health and Department for Education and Skills (2004) National service framework for children, young people and maternity services: disabled children and young people and those with complex health needs. London, Department of Health.

Department of Health and Department for Children, Schools and Families (2009) Securing better health for children through world class commissioning. A guide to support delivery of Healthy Lives, Brighter Futures: The strategy for children and young people's health. London. Department of Health and Department for Children, Schools and Families.

Dickens, M (2004) Listening to young disabled children. London. National Children's Bureau.

Dixon-Woods M et al. (1999) Partnerships with children. British Medical Journal **319**(7212): pp778-780.

Dixon-Woods M et al (2002) Lay evaluations of services for childhood asthma. Health and Social Care in the Community, **10,** pp503-511.

Educable (2000) No choice: No chance. Belfast. Save the Children.

Every Disabled Child Matters (2006) Off the radar: How local authority plans fail disabled children. Every Disabled Child Matters, London.

Farnfield S and Kaszap M (1998) What makes a helpful grown-up? Children's views of professionals in the mental health services. Health Informatics Journal, (4), pp3-14.

Fitzpatrick S et al (2000) Youth involvement in urban regeneration: hard lessons, future directions. Policy & Politics **28**(4): pp493-507.

Franck L and Callery P (2004) Rethinking of family centred care across the continuum of children's healthcare. Child: Care, Health & Development **30**(3): pp265-277.

Franklin A and Sloper P (2006) The participation of disabled children and young people in decision-making within social services departments. A national survey. British Journal of Social Work, **36**, pp723- 741.

Franklin, A and Sloper, P (2007) Participation of disabled children and young people in decision-making relating to social care. York, Social Policy Research Unit, University of York.

Franklin A and Sloper P (2009) Supporting the participation of disabled children and young people in decision making. Children and Society, Vol **23,** 1, pp 3 - 15.

Franklin A and Osborne C (2009) Independent reviewing officers communicating with children with complex communication needs. An investigation for DCSF. London. The Children's Society.

Franklin A and Knight A (2011) Someone on our side: Advocacy for disabled children and young people. London. The Children's Society.

Germain R (2004) An exploratory study using cameras and talking mats to access the views of young people with learning disabilities on their out-of-school activities. British Journal of Learning Disabilities **32**(4): pp170-174.

Greco V et al (2009) Deaf children and young people's experiences of using specialist mental health services. Children & Society **23**(6): pp455-469.

Greig R et al (2010) Short breaks pathfinder evaluation interim report - phase one. London. Department for Children, Schools and Families.

Grimshaw R and Sinclair R (1997) Planning to care: regulations, procedure and practice under The Children Act 1989. London, National Children's Bureau.

Hallstron I and Elander G (2004) Decision-making during hospitalisation: parents and childrens involvement. Journal of Clinical Nursing, **13** (3) pp367-375

Hart R (1992) Children's participation: from tokenism to citizenship. Florence, UNICEF, International Child Development Centre.

Hart R (1997) Children's participation: the theory and practice of involving young citizens in community development and environmental care. New York, UNICEF.

Heaton J and Sloper P (2004) National survey of patient advice and liaison services (PALS) in England: children, young people and parents' access to and use of PALS. Child: Care, Health and Development **30**(5): pp495-501.

Hennessy E (1999) Children as service evaluators. Child Psychology and Psychiatry Review **4**(4): pp152-161.

Her Majesty's Government (1989) The Children Act 1989. Her Majesty's Stationery Office. London, The Stationery Office.

Her Majesty's Government (2004) The Children Act 2004. Her Majesty's Stationery Office. London, The Stationery Office.

Heslop P, Mallett R, et al. (2002) Bridging the divide at transition: what happens for young people with learning difficulties and their families? Plymbridge, British Institute for Learning Disabilities.

Hill M (1997) Participatory research with children. Child & Family Social Work **2**(3): pp171-183.

HM Treasury and Department for Children Schools and Families (2007) Aiming high for young people: a ten year strategy for positive activities. London, Department for Children, Schools and Families**:** 84pp.

HM Treasury and Department for Education and Skills (2007). Aiming high for disabled children: better support for families. London, Department for Education and Skills.

Horgan G (1998) Involving children and young people in care planning.Research Policy and Planning **16**(3): pp16-22.

James A et al (1998) Theorising Childhood. Cambridge, Polity Press.

James A and Prout A (1990) Constructing and reconstructing childhood. Basingstoke, Falmer Press.

James A and Prout A (1997) Constructing and reconstructing childhood: contemporary issues in the sociological study of childhood. London, Falmer Press.

Kellet M et al (2010) WeCan2: Exploring the implications of young people with learning disabilities engaging in their own research. European Journal of Special Educational Needs, **25**, (1), pp31-44.

Kellet M (2011) Empowering children and young people as researchers. Overcoming barriers and building capacity. Child Indicators Research, **4,** 2, pp205-219

Kilgour K (2002) Circus skills: a training, support and development needs survey of participation workers. London, Carnegie Young People Initiative.

Kirby P and Bryson S (2002) Measuring the Magic? Evaluating and researching young people's participation in public decision-making. London, Carnegie Young People's Initiative.

Kirby P et al (2003a) Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation. London, Department for Education and Skills.

Kirby P et al (2003b) Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation - handbook. London, Department for Education and Skills.

Kirkbride L (1999) I'll go first: the planning and review toolkit for use with disabled children. London, The Children's Society.

Knight A (1998) Valued or forgotten? Independent visitors and disabled young people. London, National Children's Bureau.

Knight A et al (2006) The views of children and young people with learning disabilities about the support they receive from Social Services: a review of consultations and methods. London University of London, Thomas Coram Research Unit.

Laming W H (2003) The Victoria Climbié inquiry. Report of an inquiry by Lord Laming. Norwich, The Stationery Office.

Lanciano G E, O'Reilly M F, et al. (1996) A review of choice research with people with severe and profound developmental difficulties. Research in Developmental Disabilities **17**(5): pp391-411.

Lansdown G (1995) Taking part: children's participation in decision making. London, Institute for Public Policy Research.

Lansdown G (2006) International developments in children's participation: lessons and challenges. in Children, young people and social inclusion: participation for what? edited by Tisdall K, Davis J M, Hill M and Prout A. Bristol, Policy Press, pp139-158.

Lansdown G (2009) The realisation of children's participation rights: In Percy-Smith B and Thomas N eds. A handbook of children and young people's participation perspectives from theory and practice, p 11-24.

Lewis A (2004) 'And when did you last see your father?' Exploring the views of children with learning difficulties/disabilities. British Journal of Special Education **31**(1): pp3-9.

Lewis A and Porter J (2004) Interviewing children and young people with learning disabilities: Guidelines for researchers and multi-professional practice. British Journal of Learning Disability, **32,** pp191-197.

Lewis et al (2005) DRC Research report experiences of disabled students and their families: Phase 1. Birmingham, University of Birmingham.

Lightfoot J and Sloper P (2002a) Having a say in health: guidelines for involving young patients in health services development. York, Social Policy Research Unit, University of York.

Lightfoot J and Sloper P (2002b) Research works: involving young people in health service development. Social Policy Research Unit. York, The University of York. 2002-01**.**

Lightfoot J and Sloper P (2003) Having a say in health: involving young people with a chronic illness or physical disability in local health services development. Children & Society **17**(4): pp277-290.

Lord P et al. (2006) Analysis of children and young people's plans. Slough, NFER.

Loughran F et al. (1992) Children with disabilities in communal establishments: a further analysis and interpretation of the Office of Population Censuses and Survey's Investigation. Bristol, University of Bristol.

Macleman Y (2010) Talking matters. Speech and Language Therapy in Practice. Spring, 2010, p3.

Making Ourselves Heard (2009) Exploring disabled children's participation. London, National Children's Bureau.

Making Ourselves Heard and Every Disabled Child Matters (2009) Disabled children's manifesto for change. London, National Children's Bureau.

Marchant R and Page M (1993) Briding the gap: child protection work with children with multiple disabilities. London, NSPCC.

Marchant R and Crisp A (2001) What we think: views of children and young people in Southwark. Brighton, Triangle.

Marchant R and Jones M (2003) Getting it right: Involving disabled children in assessment, planning and review processes. Hove, Triangle.

Marchant R et al (1999a) Listening on all channels: consulting with disabled children and young people. Brighton, East Sussex County Council, Triangle.

Marchant R et al (1999b) 'Tomorrow I go': what you told us about Dorset Road. Young people's views about a residential respite care service. Brighton, Triangle.

Martin, K (2008) How to involve children and young people with communication impairments in decision-making. National Children's Bureau, London.

Martin K and Franklin A (2009) Disabled children and participation in the UK: Reality or rhetoric? In Percy-Smith B and Thomas N eds. A handbook of children and young people's participation perspectives from theory and practice, p 97 - 105.

Matthews H (2001) Citizenship, youth councils and young people's participation. Journal of Youth Studies **4**(3): pp299-318.

Matthews H (2003) Children and regeneration: setting an agenda for community participation and integration. Children & Society **17**(4): pp264-276.

Mayall B (1994) Children's childhoods: observed and experienced. London, Falmer Press.

Mayall B (1996) Children, health and the social order. Buckingham, Open University Press.

McNeish D (1999) Promoting participation for children and young people: some key questions for health and social welfare organisations. Journal of Social Work Practice **13**(2): pp191-203.

McNeish D and Newman T (2002) Involving children and young people in decision making. in What works for children? Effective services for children and families edited by McNeish D, Newman T and Roberts H. Buckingham, Open University Press, pp186-204.

MENCAP (2003) Listen up: helping children with a learning disability complain about the services they use. London, MENCAP.

Minkes J, et al. (1994) Consulting with children: interviews with children using residential respite care services. Disability & Society **9**(1): pp47-57.

Mitchell W and Sloper P (2001) Quality in services for disabled children and their families: what can theory, policy and research on children's and parents' views tell us? Children & Society **15**(4): pp237-252.

Mitchell W et al (2009) Working with children with learning disabilities and/or who communicate non-verbally. Research experiences and their implications for social work education, increased participation and social inclusion. Social Work Education, **28**, 3, pp309-324.

Mitchell, W. (2010a) 'I know how I feel': Listening to young people with life-limiting conditions who have learning and communication impairments. Qualitative Social Work, **9** (2): p185-203.

Mitchell, W. (2010b) Making choices in my life: Listening to the ideas and experiences of young people in the UK who communicate non-verbally. Children and Youth Services Review, 33 (4), pp521-527.

Mitchell W and Sloper P (2010) Making choices in my life: Listening to the ideas and experiences of young people in the UK who communicate non-verbally. Children and Youth Services Review, **33,** 4, pp521-527.

Morris J (1995) Gone missing? A research and policy review of disabled children living away from their families. London, The Who Cares? Trust**:** 106pp.

Morris J (1998a) Don't leave us out: involving disabled children and young people with communication impairments. York, Joseph Rowntree Foundation.

Morris J (1998b) Still missing? Volume 1: the experiences of disabled children and young people living away from their families. London, The Who Cares? Trust.

Morris J (1998c) Still missing? Volume 2: disabled children and the Children Act. London, The Who Cares? Trust.

Morris J (1999a) Hurtling into a void: transition to adulthood for young disabled people with complex health and support needs. Brighton, Pavilion Publishing.

Morris J (1999b) Space for us: finding out what disabled children and young people think about their placements. London, Newham Social Services.

Morris J (2001a) Social exclusion and young disabled people with high levels of support needs. Critical Social Policy **21**(2): pp161-183.

Morris J (2001b) That kind of life? Social exclusion and young disabled people with high levels of support needs. London, Scope.

Morris J (2002) A lot to say! A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments. London, Scope, The Community Fund.

Morris J (2003) Including all children: finding out about the experiences of children with communication and/or cognitive impairments. Children & Society **17**(5): pp337-348.

Morrow V and Richards M (1996) The ethics of social research with children: an overview. Children & Society **10**(2): pp90-105.

Noyes J (1999) Voices and choices. Young people who use assisted ventilation: their health and social care and education. London, The Stationery Office.

Noyes J (2000) Enabling young 'ventilator-dependent' people to express their views and experiences of their care in hospital. Journal of Advanced Nursing **31**(5): pp1206-1215.

NSPCC (2003) It doesn't happen to disabled children. London, NSPCC.

O'Mahony C (2010) Pushing for change. The role of disabled people's organisations in developing young disabled leaders of the future. London. ALLFIE

O'Sullivan T (1998) The transition of young adults with disability: a study of the effectiveness of inter-agency transitional planning - executive summary. London, Department of Health.

Oldfield C and Fowler C (2004) Mapping children and young people's participation in England. Nottingham, Deparment for Education and Skills.

Oliver C (2003) Advocacy for children and young people: a review. London, Institution of Education, University of London.

Oliver M (1983) Social work for disabled people. Basingstoke, MacMillan.

Participation Works (2008a) Listen and change: A guide to children and young people's participation rights. Children's Rights Alliance for England, London.

Participation Works (2008b) Evaluating participation works. The Guide. London.

Petrie P et al (2000) Out-of-school lives, out-of-school services. London, The Stationery Office.

Petrie P et al (2002) Inclusive play: supporting provision for disabled children. London, University of London,Institute of Education.

Preece D (2002) Consultation with children with autistic spectrum disorders about their experience of short-term residential care. British Journal of Learning Disabilities **30**(3): pp97-104.

Prendergast S (1992) This is the time to grow up: girls' experience of menstruation in school. London, Family Planning Association.

Prewett B (1999) Short-term break, long-term benefit: using family-based short breaks for disabled children and adults. York, Joseph Rowntree Foundation.

Priestley M (2000) Adults only: disability, social policy and the life course. Journal of Social Policy **29**(3): pp421-439.

Priestley M et al (2003) Young disabled people and the 'new arrangements' for leaving care in England and Wales. Children and Youth Services Review **25**(11): pp863-890.

Prout A (2003) Participation, policy and the changing conditions of childhood in Hearing the voices of children: social policy for a new century edited by Hallet C and Prout A. London, Routledge Falmer, pp11-25.

Rabiee P et al (2001) Whatever next? Young disabled people leaving care. Leeds, First Key.

Rabiee P et al (2005a) Desired outcomes for children and young people with complex health care needs, and children who do not use speech for

communication. Health and Social Care in the Community **13**(5): pp478-487.

Rabiee P et al (2005b) Doing research with children and young people who do not use speech for communication. Children & Society **19**(5): pp385-396.

Robbins D (2001) Transforming children's services: an evaluation of local responses to the Quality Protects programme year 3. London, Department of Health**.**

Royal College of Paediatrics and Child Health (2010) Not just a phase: A guide to the participation of children and young people in health services. London, Royal College of Paediatrics and Child Health.

Russell P (2003) Access and achievement or social exclusion?' Are the government's policies working for disabled children and their families?" Children & Society **17**(3): pp215-225.

Sartin S.A et al (2000) Hearing the voices of children with chronic illness. Journal of Advanced Nursing, (32), pp913-921.

Shakespeare T and Watson N (2002) The social model of disability: an outdated ideology? Research in Social Science and Disability **2**: pp9-28.

Shier H (2001) Pathways to participation: openings, opportunities and obligations: a new model for enhancing children's participation in decision-making, in line with Article 12.1 of the United Nations Convention on the rights of the child. Children & Society **15**(2): pp107-117.

Sinclair R (2004) Participation in practice: making it meaningful, effective and sustainable. Children & Society **18**(2): pp106-118.

Sinclair R and Franklin A (2000) Quality Protects research briefings: young people's participation. Department of Health, Research in Practice and Making Research Count. London, Department of Health**:** 8pp.

Sloper P, et al (2009) Every Child Matters outcomes: what do they mean for disabled children and young people. Children & Society **23**(4): pp265-278.

Sloper P et al (2010) Models of multi-agency services for transition to adult services for disabled young people and those with complex health needs: impact and costs. York, The University of York.

Spicer N and Evans R (2006) Developing children and young people's participation in strategic processes. The experiences of The Children's Fund initiative. Social Policy and Society, 5, pp177-188.

Stalker K and Connors C (2003) Communicating with disabled children. Adoption & Fostering **27**(1): pp26-35.

Stalker K et al (2003) Children with complex support needs in health care settings for long periods. Summary. York, Joseph Rowntree Foundation.

Stalker K et al (2010) Child protection and the needs and rights of disabled children and young people: a scoping study - abridged report. Glasgow, The University of Strathclyde.

Stone E (2001) Consulting with disabled children and young people. York, Joseph Rowntree Foundation.

The Children's Society (2001) Ask us: a Children's Society multi-media guide to consultation for the Quality Protects initiative. London, The Children's Society.

The Children's Society (2002) Young people's charter of participation. London, The Children's Society.

The Children's Society (2007) When will we be heard? Advocacy provision for disabled children and young people in England. London, The Children's Society.

The National Evaluation of the Children's Fund and Department for Education and Skills (2004) Children, young people, parents and carers' participation in Children's Fund case study partnerships - research report 602. Nottingham, Department for Education and Skills.

Thoburn J, et al (1995) Paternalism or partnership? Family involvement in the child protection process. London, HMSO.

Thomas N and O'Kane C (1999) Experiences of decision-making in middle childhood: the example of children 'looked after' by local authorities. Childhood **6**(3): pp369-387.

Together for Disabled Children (2010) Is the voice of the child having an impact on the development of short breaks? A small-scale survey that explores whether the 'Aiming High for Disabled Children: Short Breaks Programme' has enabled effective participation of disabled children and young people to take place. Birmingham. Together for Disabled Children.

Treseder P (1997) Empowering children and young people: training manual. London, Children's Rights Office, Save The Children.

United Nations (1989) Convention on the rights of the child. Geneva, United Nations.

United Nations (2006) Convention on the rights of persons with disabilities. New York, United Nations.

United Nations Committee on the Rights of the Child (1997) General discussion paper on children with disabilities, United Nations.

United Nations (2008) Concluding observation on the UK compliance with the Convention on the Rights of the Child. United Nations.

University of East Anglia and National Children's Bureau (2005) Realising children's trust arrangements: national evaluation of children's trusts - phase 1 report. Norwich, University of East Anglia.

Utting W (1997) People like us: the report of the review of the safeguards for children living away from home. London, Department of Health.

Ward L (1997) Seen and heard: Involving disabled children and young people in research and development projects. York, Joseph Rowntree Foundation.

Ward L et al (2003) Transition planning: how well does it work for young people with learning disabilities and their families? British Journal of Special Education **30**(3): pp132-137.

Ware J (2004) Ascertaining the views of people with profound and multiple learning disabilities. British Journal of Learning Difficulties **32**(4): pp175-179.

Waterhouse R (2000) Lost in care: report of the tribunal of inquiry into the abuse of children in care in the former council areas of Gwynedd and Clwyd since 1974. London, Department of Health.

Watson D et al (2006) Listen to me, too! Lessons from involving children with complex health care needs in research about multi-agency services. Child: Care, Health & Development **33**(1): pp90-95.

Watson, D et al (2007) I want to choose too. A resource for teachers and others including primary school age children with little or no speech in decision-making. University of Bristol, Bristol.

Westcott H L (1993) Abuse of children and adults with disabilities. London, NSPCC.

Williams F (2004) What matters is who works: why every child matters to New Labour: commentary on the DfES Green Paper Every Child Matters. Critical Social Policy **24**(3): pp406-427.

Williamson B (2003) The grit in the oyster: final report of the evaluation of investing in children. Durham, University of Durham.

Willow C (2002) Participation in practice: children and young people as partners in change. London, The Children's Society.

Willow C et al (2004) Young children's citizenship: ideas into practice. York, Joseph Rowntree Foundation.

Wilson, C and Jade, R. (1999) Whose voice is it anyway? Talking to disabled young people at school. London. Alliance for Inclusive Education.

Wright J A, et al (2006) Communication aids in the classroom: the views of education staff and speech and language therapists involved with the Communication Aids Project. British Journal of Special Education **33**(1): pp25-32.

Young, B et al (2003) Managing communication with young people who have a potentially life threatening chronic illness: Qualitative study of patients and parents. British Medical Journal, pp326:305