TITLE: **Listening and Responding? Children's Participation in Health Care within England**

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This article was published March 2005 in:

Franklin, A. and Sloper, P. (2005) Listening and responding? Children's participation in health care within England, *International Journal of Children's Rights*, 13, 1/2, 11-29.

Link to the online version:
http://springerlink.metapress.com/content/w76403471957/?p=1f94ffc04fd5411ea310e7b8d5ed80b6&pi=4

DOI: 10.1163/1571818054545277

Listening and responding? Children's participation in health care within England

Introduction

This article examines recent health policy developments in England in relation to children's rights under Article 12 and 13 of the United Nations Convention on the Rights of the Child (UNCRC). It draws on practice and research literature to explore evidence regarding: children's participation both within decisions about their own care and concerning the development of health services, their access to mechanisms that allow them a voice, the provision of and need for accessible information, and factors which prevent or facilitate children's participation. This paper does not explore in detail issues concerning children's consent or competence to participate, for authoritative accounts on these subjects, see for example, Alderson and Montgomery, 1996; Alderson, 2000; British Medical Association, 2001; Department of Health, 2001a.

Figure One: Article 12 and Article 13 of United Nations Convention on the Rights of The Child (1989)

Article 12

1. States 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.

2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

Article 13

1. The child shall have the right to freedom of expression; this right shall include 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.

The term children is used to describe children and young people and does not specify an age range thus reflecting the variation and ambiguity of age range within much of the literature on children's participation.

Policy on involving children and young people

Children's rights to expression and to receiving information are underpinned by Articles 12 and 13 of the United Nations Convention on the Rights of the Child (UNCRC). The UK Government ratified the UNCRC in 1991, in the intervening years participatory initiatives and consultations have grown across social care, health and education (Willow, 1997, 2002; Department of Health, 1999, 2001b, 2003a; Sinclair and Franklin, 2000; Cavet and Sloper, 2004; Sinclair, 2004).

Within England there is widespread acknowledgment that children should be involved in decisions which affect them. This is reflected in existing law, government guidance, regulations and policy. The Human Rights Act, 1998 (Article 10) requires central and local government to uphold a right to freedom of expression and the Children Act 1989 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, plus the child's age and understanding. For disabled children, guidance and regulations (Department of Health, 1991) make it clear that, if a child has complex needs, communication difficulties or severe learning difficulties, arrangements must be made to establish their views, and that a disabled child cannot be assumed to be incapable of sharing in decision-making.

Even the structures and culture of central government have to some extent embraced participation with the establishment of young people's advisory fora, and the publication of a framework of core principles for children and young people's involvement across all government departments. Alongside this is the requirement for all central government departments to produce associated Action Plans detailing how they are to involve children and young people in the decision-making of their department (Children and Young People's Unit, 2001).

> *"The government want children and young people to have more opportunities to get involved in the design, provision and evaluation of policies and services that affect them or which they use"* (Children and Young People's Unit, 2001, p2)

In addition, the government has started to address the need for accessible information for young people by making some of its websites and reports of consultation results available in child-friendly formats (See website: http://www.cypu.gov.uk)

Within health care, service users in general are being 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, new national requirements for patient and public involvement place a duty on service providers to involve children and young people (Department of Health, 1999, 2001b, 2003a, 2003b). The Department of Health documents 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.

> *"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).

Within England, the Children's National Service Framework (NSF) is soon to be published. The NSF will set standards aimed at raising the quality of the health and social care services that children receive. The Framework has a broad remit and it stresses the need to consult and involve children: the standard for hospital services states that "children, young people and their parents will participate in designing NHS [National Health Service] and social care services that are readily accessible,

respectful, empowering, follow best practice in obtaining consent and provide effective response to their needs" (Department of Health, 2003b, p9).

Since 2002, all English NHS and Primary Care Trusts, have been required to establish a Patient Advice and Liaison Service (PALS). This service seeks to enable patients and the public, including children and young people, to access information and raise issues of concern (Department of Health, 2000; 2001c).

Professional organisations have also recognised the importance of involving children and young people. The British Medical Association (2001) states that health professionals should ensure the participation of children and young people in all aspects of decision-making about their healthcare and that health professionals should take all reasonable steps to enhance the ability of children to participate in decision-making.

However, despite legislative requirement and a shift in philosophy, the Government's commitment to children's participation has been criticised by the UN Committee reviewing the UK Government's implementation of the UNCRC. Whilst recognising the increased emphasis placed on participation by the Government, the Committee felt there was still more to do, especially in ensuring that participation leads to change.

> *"The Committee recommends that the State party, in accordance with Articles 12 and 17, take further steps to promote, facilitate and monitor systematic, meaningful and effective participation of all groups of children…*

> *The Committee further recommends that procedures be formed to acknowledge publicly the views expressed by children and the impact that they have on developing programmes and policies, and reflect how they are taken into consideration"* (Committee for the Rights of the Child, 2002, p7, quoted in Sinclair, 2004, p110)

The movement towards involving children in their healthcare is based on the growing body of evidence demonstrating children's competence to be involved in decisions about their health and care, and about the relevance of experience to competence (for example, Alderson, 1993; Eiser, 1993; Rylance, 1996). Children with experience of severe illness or disability, especially, can contribute unique and essential knowledge during decision-making, which must be given serious consideration when helping children and parents decide about consent to treatment (Alderson, 1993; Alderson and Montgomery, 1996). Five years ago, Dixon-Woods et al. (1999) wrote that evidence suggests that partnership with children enjoys only limited success. Children are given little voice in medical consultations and are rarely consulted as partners in the evaluation and planning of health services. So what is the reality five years on, does the evidence suggest movement towards more participatory practice and accessible information for children and young people within healthcare?

What is meant by participation?

The term "participation" covers a broad continuum of involvement in decisions; it is a multi-layered concept, involving many different processes (see e.g. Kirby et al, 2003a; Sinclair, 2004). Boyden and Ennew (1997) state that there are two interpretations of the term 'participation'. It can simply mean taking part, being

present or consulted. Alternatively, it can denote a transfer of power so that participants' views influence decisions. A number of writers have developed typologies to illustrate this. These generally make hierarchical distinctions between levels of participation according to the degree of power that is shared or transferred, usually depicted as steps on a 'ladder of participation'. Arnstein (1969) first developed the ladder of participation in relation to citizen involvement in community development, Hart (1992, 1997) adapted this for children's participation and a number of variations on this have followed, including Shier (2001) who attempts to create a "pathway to participation". Shier adapts the ladder to help practitioners to explore the participation process, determine their current position and identify the necessary steps to be taken to increase their level of participation (see also for example, Thoburn et al., 1995; McNeish and Newman, 2002). These typologies have been criticised as they suggest a hierarchy with the objective being to reach the highest level, where children are the main decider (Treseader, 1997; Willow, 1997; Lardner, 2001). However, participation rights do not necessarily confer the right to be the main decider, nor do children want to exclude their parents and other adults from the process (Lansdown, 1995; Alderson and Montgomery, 1996; Morrow, 1998). Studies have also shown that children and young people recognise the limits of their autonomy and accept their need for adult guidance and support (Newman, 1996; Morrow, 1998).

Recently, Kirby et al. (2003a) have developed a non-hierarchical model of participation, where no one level is assumed to be superior to another, instead the type of participation activity will be determined according to the circumstances and the participating children and young people. 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 within England, that the level of children's participation will vary depending on the decisions involved and the capability and choice of the child. However, meaningful participation must also be seen as a process not simply an isolated activity or event (Kirby et al., 2003a).

Alderson and Montgomery (1996) define four levels at which children can participate;

1. Being informed
2. Expressing a view
3. Influencing a decision
4. Being the main decider

Taking Alderson and Montogomery's example, all levels are important methods of participation and the first three precede the fourth if the child is to make an informed choice. The first three levels are contained within the UNCRC and include any child who can firstly, understand information, secondly, form a view and finally, is considered to be able to form a view which can usefully inform the decision-making process. This model provides a useful framework to examine the evidence of children's participation within healthcare in England at this present time.

Provision and need for accessible information

Genuine participation is based on informed consent and requires that children and young people are given 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, it is the first and vital stage of the process. Children in hospital settings, for example, need to be informed about who is responsible for telling them what is happening, what the implications of treatment are, side effects, options that are available, implications of not having the treatment, whether it will hurt and how long it will take (Lansdown,1995).

While it is arguable that Article 12 is limited by reference to particular attributes of the child, namely their capacity, age and maturity, Article 13 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 younger children and disabled children, especially those with communication related impairments. The Department of Health states explicitly that a child who is learning disabled 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, 2001a, p4). Parents and health practitioners have a clear duty under Article 12 to ensure that the child has been given both the time and information they need to be helped to make an informed choice.

However, evidence on children's experiences 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. Bradding and Horstman (1999) found that chronically ill children had information needs within four domains: diagnosis, treatment, prognosis and "supportive", the need for honest, accurate information given within a supportive environment was evident. Beresford and Sloper's (1999) research with 63 young people affected by six chronic conditions identified their views on medical and psychosocial information needs which must be met to promote physical and emotional well being. These included medical information on factors such as the condition, general human biology, treatments, tests and investigations, managing exacerbation, lifestyle factors, current research and health and other sources of statutory support. Psychosocial information needs included dealing with negative emotions, living with physical symptoms, living with unanswered questions, dealing with parents and peers, managing at school and in other social settings, living with restrictions on lifestyle, maintaining a positive attitude and planning for the future. The young people also highlighted the important role of their parents as information providers, indicating that parents' information needs must also be addressed.

Changing needs mean regular information is required, delivered in a variety of ways, appropriate to the needs of the young person. Dixon-Woods et al. (1999) state that there is a scarcity of evidence about how to design information materials for children. However, Alderson and Montgomery (1996) offer practical suggestions on the type of information which should be shared with children involved in decision-making in health care settings, such as information on their condition, purpose of treatment,

hoped for benefits, timing and nature of treatment/investigation, risks involved and possible harm and inconvenience it will cause (pain, scarring, follow-up clinics etc). They also suggest how practitioners might check young patients understanding of this information. For example, through the questions young patients might ask, their expression of hopes, fears and of what might be in their best interest. Brook (2000) has developed a framework for children to be involved in decisions about proposed liver transplant, although the framework is applicable to many situations. The framework highlights the uniqueness of each child and their family, the necessity of keyworkers to co-ordinate information sharing and the need for an open, friendly approach which *shares* information and does not *give* information. Privacy, sensitivity and an allowance of adequate time are deemed essential.

Access to mechanisms to allow children and young people to voice their views

The second stage of Alderson and Montgomery's model describes children expressing a view, however, genuine participation requires that this 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). 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).

Patient Advice and Liaison Service have recently been established within all English NHS and Primary Care Trusts, to provide an easily accessible service for people with concerns about their care. However, research suggests 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, 2003). Nevertheless there are some attempts being made to make mechanisms for complaints accessible to children, for example, MENCAP have recently developed a resource pack to assist children with a learning disability to complain about the services they use (2003).

Some literature points to the necessity of not only formal mechanisms through which children 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, 2003; Kirby et al., 2003a, 2003b). Studies in the main concentrate on formal mechanisms, but Lightfoot and Sloper's study found that young people urged an informal approach, in addition to formal structures and dedicated 'participation workers' (2002, 2003).

Focus of participation activity

It is important when examining participation to distinguish the focus of children's participation which can vary. The third level of Alderson and Montgomery's model involves young people influencing decisions and children and young people can influence decisions in matters which affect them as individuals (personal or individual

decisions) and those which relate to them as a group (public decision-making), for example within service planning and development, or influencing policymaking. Both are important, but the mechanisms to achieve involvement are likely to be different.

Evidence of individual participation in health care

Published literature within this area of participation has mainly focused on children's competency to be involved in decisions about their health care and treatment. Most studies have concentrated on children with serious health problems or disabilities, where results have shown that when children acquire knowledge about their condition, treatment, likely pain and prognosis, they are more willing to co-operate with treatment, they understand better when and why to take drugs, they endure painful treatments more patiently and recover better (Alderson, 2000; Tates and Meeuwesen, 2001). Cavet and Sloper (2004) summarised the evidence on programmes or strategies designed to improve the knowledge of children and young people regarding their medical condition and concluded that they tended to show positive results (e.g. Bradbury et al. (1994) regarding hand surgery for children with missing fingers; Booth et al (1995) about cochlear implants; Brook (2000) concerning children with liver disease; Barlow and Harrison (1996) regarding juvenile arthritis and volunteer contact; Lewis (1991) cited in a review by Lewin et al (2002) about medical interviews with children and their parents; Bartholomew et al (1997) regarding children with cystic fibrosis).

Alderson (2000) quotes a number of examples of very young children with life-threatening illnesses being consulted and taking a very active role in their treatment. These include two-year old children with cancer understanding the names of their

medication, the purpose of them and cooperating with their treatment (Kendrick et al., 1986) and a seven year old child weighing up the risks and benefits of having a heart and lung transplant (Alderson, 1993).

Evidence however, suggests that the involvement of children is patchy and requires further development. For example, research shows that the conversational contribution of the child in medical encounters is slight (Tates and Meeuwesen, 2001) and Obigwe (2004) quotes evidence from a database complied by The Commission for Health Improvement, which states that children and young people are unhappy with the lack of communication they get when they are treated in the NHS and that they are not sufficiently involved within the decision-making process. The database contains the results of 59 separate reports of feedback from children and young people about health care (see www.chi.nhs.uk//childrens_voices).

There is limited evidence on which children are being involved in participation activity but the evidence available 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. Concerns about the participation of young people from socially excluded groups have been raised by several authors (e.g. McNeish and Newman, 2002; Cutler and Frost, 2001) Younger children, children with communication difficulties and those with minimum involvement with local agencies have been identified as least likely participants (Sinclair, 2004). Cavet and Sloper (2004) summarise studies which suggest that some disabled children are not being afforded their full rights regarding participation, in particular ‘ventilator dependent’

young people (Noyes, 2000), those looked after by the local authority (Morris,1998a, 1998b) 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 the children's involvement in decision-making (Stone, 2001; Morris,1998a; Rabiee et al., 2001). Marchant and Jones (2003) note the linguistic and cultural barriers to involvement faced by disabled children from ethnic minority groups.

The literature to date has in the main concentrated on children's competency to participate, although there are increasing numbers of studies reporting successful participation of children within their own health care. However, there is no evidence yet to suggest that this is widespread practice, and clearly some children, such as those with disabilities, are generally not being involved. There has been little data collected on the approaches undertaken by practitioners, children's experiences of involvement, and on the outcomes for children, parents, professionals and services.

Evidence of participation in public decision-making regarding health care

Children have a lot to tell us about their access to and experiences of health services and resources and this area has received more attention, with children increasingly being consulted about a range of issues concerning health services (for example, Elliot et al., 1996; Noyes, 2000; Jones et al., 2000; Gleeson et al, 2002; Liabo et al., 2002; Madge and Franklin, 2003). Young people have been involved in developing a children's version of the Department of Health Drug Strategy (Department of Health, 2003a) and disabled children have expressed their views about what constitutes quality in services (Mitchell and Sloper 2001). Bradding and Horstman (1999)

describe using the draw and write technique to allow young chronically ill children to express their views about hospitals, health professionals and health information needs.

However, there is little evidence that collates the disparate reports published on what help and information children and young people want, where they go for help, and what gaps there are in formal and informal provision. Children and young people are ever more being asked for their opinions on services, yet there is a lack of data on how their views are feeding into the subsequent decision-making processes, which could led to disillusionment among young people who see little evidence that their views are being taken seriously (Sinclair, 2004).

Cutler and Frost (2001) mapped young people's involvement in public decision-making and concluded that within health promotion young people's participation was in evidence. They highlighted government initiatives such as the National Healthy School Standard (NHSS), which aims to help schools become healthier places and places pupil participation high on the agenda. However, Culter and Frost found little evidence of young people's participation in health treatment services or indeed, information on good practice within this area. They highlighted one study by Lightfoot and Sloper (2002) which identified 27 examples of local health services which consulted children who were chronically ill or physically disabled, of which 11 involved young people in subsequent decisions about service development. Clearly, this is a need for more evidence of this kind to illuminate the approaches undertaken, document the experiences of those involved and to learn more about how or if children's views are influencing the decisions being made.

Barriers to young people's participation

Although children and young people's participation is part of international law and on the agenda of the government, there is evidence of a number of barriers that prevent effective participation (see for example, Alderson and Montgomery, 1996; Alderson, 2000; Willow, 2002). Lansdown (1995) notes that a commitment to respect the participation rights of children represents a significant shift away from traditional understandings of children's status in society, and provokes concerns about its implications for adult/child relations. Participation raises questions about children's status, lack of power and the need for widespread changes to how we view children.

Some barriers identified pertain to the complexity and bureaucratic nature of organisations (Matthews, 2001; Kirby and Bryson, 2002, Kirby et al., 2003a, 2003b); to adult attitudes, particularly concerning the capabilities and competence of children, and the need to protect children (Matthews, 2001; Bell et al., 2002; Kirby and Bryson, 2002); to a lack of relevant training and support for adult facilitators and young people participating (Kirby and Bryson, 2002); a lack of research evidence to support participatory activities (Dixon-Woods et al., 1999; Hennessy, 1999); and practical barriers such as time, resources and dedicated funding (NcNeish and Newman, 2002).

It should not be overlooked that young people themselves can form a barrier (McNeish and Newman, 2002). Young people may have fixed ideas about adults, or generally not have positive relationships with them. They may also lack self-esteem and confidence or their personal circumstances may not be conducive, for example if

they are carers or lack transport. Of course, children and young people may not want to take part or have other competing priorities on their time.

Factors which facilitate young people's participation

Although a large number of guides and checklists on good practice in involving children in decision making exist (for examples, see Ward, 1997; Treseder, 1997; Beecher, 1998; Cohen and Emmanuel, 1998; Morris, 1998c, 2003; McNeish, 1999; Kirkbride, 1999; Shier, 2001; Clark and Herts, 2000; Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; Clark and Moss, 2001; Wade and Badham, 2001; Lightfoot and Sloper, 2002; Coombe, 2002; The Children's Society, 2002; Marchant and Jones, 2003; Culter, 2003; Kirby et al., 2003a, 2003b), it is not always clear where the evidence for this advice on good practice has come from. In most cases, evidence has been gathered from adult facilitators of participation activity, there is little evidence from children about their experiences of involvement, although some data are emerging (Matthews, 2001; Coombe, 2002; Lightfoot and Sloper, 2002, 2003; Kirby et al., 2003a).

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

- *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). 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 activity. When children are approached to participate they need clear, accessible information about what participation will entail and what participation will hopeful achieve, and arrangements regarding confidentiality, anonymity, and the option to opt out (Alderson, 1995; Sinclair and Franklin, 2000; Lightfoot and Sloper, 2002, 2003).

- *Staff training and development*

The need for staff training and skills development in order to promote participation in decision-making by children is highlighted in several studies (Hennessy, 1999; McNeish et al., 2000; Children's Taskforce, Department of Health, 2001; Kirby and Bryson, 2002; McNeish and Newman, 2002; Lightfoot and Sloper, 2002, 2003; Kilgour, 2002). Attitudinal changes in health professionals are required about childhood and adolescence, particularly concerning consent and competence (Alderson and Montgomery, 1996); about communication (Beresford and Sloper, 1999); and about the idea of partnership between healthcare professionals and their patients (Bristol Royal Infirmary Inquiry, 2001). Beresford and Sloper (1999) highlight the need for skills development with regard to communication, with the suggestion that this will be more effective if young people's communication skills are also developed.

- *Using flexible and appropriate methods*

There are a number of publications that highlight the advantages and disadvantages of numerous methods of involving children and young people 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, 2002, 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, however their conclusions may equally apply to other 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;
- multiple contacts in order to get to know the young person;
- flexibility about how children participate and recognising that children communicate in mediums other than speaking;
- independent facilitators so that children can give their views about services they use in confidence;
- and the need to make participation fun and rewarding.

- *Organisational culture, systems and structures*

It is recognized 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). Kirby et al. (2003a), highlight how genuine participation is a process and not an isolated event, and thus requires organisations to change 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. They state that the key to this is senior management support and a mainstreaming of practice.

- *Assessing and evidencing the impact of children's participation*

Badham (2004) argues that it is often unclear how the process of participation is meant to link with better outcomes for the intended beneficiaries and what is actually changing for children and young people as a result of their involvement. Despite a growth in participation activity, there is a lack of evaluation in terms of process and outcomes, both internally and externally (Kirby and Bryson, 2002; Cavet and Sloper, 2004; Sinclair, 2004).

For many, children's participation is a value or 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. Some moves have been made in this direction with the Department of Health (2003a) prioritising this within their action plan and

recent work funded by the Children and Young People's Unit (Kirby et al., 2003a, 2003b). There is also increasing pressure to develop national minimum standards of participation and charter marks for organisations undertaking participatory activities (Culter, 2003).

Concluding comments

Within England, the value of involving children and young people is accepted by government and is continuing to be reflected in policy. However, it would appear that participation practice is limited and patchy and, particularly within service development, may only be occurring at relatively lower levels of decision-making (CR Team Article 12, 1999; Lightfoot and Sloper, 2003). There is little published evidence, as yet, to suggest that there is successful participation across all levels of Alderson and Montgomery's model. Change and challenge lies ahead if participation is to become embedded and sustained. Equally of concern is the limited evidence of equality of participation across the whole population of children and young people (Kirby and Bryson, 2002; Sinclair, 2004; Cavet and Sloper, 2004). The exclusion of some groups of young people, particularly disabled children, younger children and those from marginalised groups, from the participation process has been raised by a number of authors (McNeish et al., 2000; NcNeish and Newman 2002; Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; Lightfoot and Sloper, 2003; Sinclair, 2004).

Checklists and guides cannot achieve the long-term inclusion of children and young people in decision- making alone, although they can help to support initiatives and

help to launch activity (Willow, 2002). However, sustained change can only come through breaking down the barriers to children's participation.

The challenges which lie ahead include the need to demonstrate the extent of young people's involvement, the collation of evidence from children and young people about their own experiences of participation, and evidence on how participation can become embedded and sustained. Internal and external evaluations are needed on the process and outcome of participation. Dixon-Woods et al (1999) argue that, "the aspirations of the children's rights movement will have little chance of being realised until there is more research based evidence on outcomes of shared decision-making, how the competence of children can be assessed, how information can be shared with children and how shared decision-making should be managed in practice" (p778).

Sinclair (2004) states that with 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 describes the current situation with regard to children being involved in their health care. Reports have documented the rights of children, and offered practical steps for participation and information provision. However, much is left to learn about who is being involved, how they are being involved and the outcomes of their involvement.

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