Is children's choice in health care rhetoric or reality? A scoping review

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Abstract

Title. Is children's choice in health care rhetoric or reality? A scoping review.

Aim. This paper is a report of a scoping review examining children and young people's health services with respect to choice in order to inform future development of choice initiatives.

Background. The importance of including children and young people in the choice agenda reflects the increasing acknowledgement that, individually and collectively, they are important consumers of health care in their own right.

Data sources. A scoping review of all major health and medical research databases was undertaken using current guidelines to identify original relevant research papers and grey literature sources from 1990 to 2006.

Review methods. Reference Manager software was used to collate, summarize, categorize, store and retrieve the search results. Papers meeting the inclusion criteria were read in full and descriptively summarized using a data extraction sheet. Each paper was repeatedly selected using a snowballing approach until saturation was reached.

Results. Children and young people want more say in the planning and development of appropriate hospital and community health services. However, little evaluative research was found about whether these choices are acted upon and lead to more responsive services.

Conclusion. Choice for children and young people is viewed as a positive development in health care and many innovative examples of their involvement in decision-making were found. These illustrated that, given the opportunity, children and young people are willing and able to make decisions about their healthcare services. However, there is a long way to go before the rhetoric of the choice agenda is realized.

Keywords: children and young people, choice, decision-making, information, nursing, scoping review

Introduction

Children and young people are significant users of health services and are a specific population with special requirements for care (Aynsley-Green *et al.* 2000). The United Nations Convention on the Rights of the Child (UNCRC 1989) calls for states to:

assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (Article 12)

Consequently, a large international body of policy-makers and pressure groups (government and voluntary) has grown

up in response to Article 12. These are united in a firm conviction about the importance of involving children and young people in decision-making, an agenda which overlaps with democratization, citizenship and choice. It is believed that giving patients a real choice about the services they receive will drive up standards, improve efficiency and increase patient-centred care. The concept of children and young people having 'choice' in health care has thus gathered pace internationally, most notably in developed countries (Stewart 2001, Portero *et al.* 2002, Cavet & Sloper 2004a, 2004b, Hallstron & Elander 2004, Villalon & Leclair 2004, Boshoff *et al.* 2007, Coad & Houston 2007).

In the United Kingdom (UK), the 'Choice' initiative was explicitly raised in the National Health Service (NHS) modernization agenda (DH 2003). The importance of including children and young people in this choice agenda acknowledges that, individually and collectively, they are important consumers of health care in their own right. This includes services supporting choice, user involvement, the realignment of the health and social care system, and services that meet local needs (DH 1999, 2001a, 2001b, 2003, 2004, 2005, 2006). There are also legal requirements to involve children and young people in decisions that affect their lives (e.g. UNCRC 1989, Article 12). However, as Hill *et al.* (2004) suggest, children remain over-governed by both the state and civic society and have been traditionally regarded as lacking the social or cognitive competence to make informed decisions about their lives. Whilst this paternalistic approach has been largely motivated by a wish to protect children, the views of adults do not necessarily represent those of children individually or collectively (Beresford 1997, Hart & Chesson 1998, Coad & Lewis 2004, Viner & Barker 2005, Coad & Houston 2007).

It is against this backdrop that the current paper is set and outlines a scoping review that examines the extent to which children and young people are offered 'real' choices in their personal health care and service development. The intention behind the work was to inform future development of choice initiatives for children and young people aged 5–18 years in the UK.

The review

Aim

The aim of the review was to examine children and young people's health services with respect to choice. The following research questions were addressed:

- What evidence is there that children and young people are being offered choice in health services?
- What are the barriers to offering choice to children and young people?
- What can promote choice for children and young people?

Design

A scoping review was carried out.

Search methods

The search strategy paralleled established approaches taken in major reviews such as the Centre for Reviews and Dissemination Handbook (CRD 2001). Electronic databases including Medline; Social Care Online; Cumulative Index of Nursing & Allied Health Literature (CINAHL); PsychLIT; and Social Science Citation Index (SSCI) were used. Results were supplemented with other papers known to the authors and 'grey literature' identified by contacting relevant organizations and individuals (e.g. Royal College of Nursing, Action for Sick Children, National Children's Bureau, INVOLVE, Carnegie Young People Initiative, Joseph Rowntree Foundation, King's Fund, National Youth Agency and Social Policy Research Unit).

The search terms included choice, prefer, priorities, health care, health and social care services, participant, involve, communicate, decision-making, perspective and views in combination with child, young person, adolescent, patient, user, consumer or client (in title). The search was limited to papers published in English between 1990 and 2006. Preference was given to UK literature, although international publications were considered where relevant. Reference Manager software was used to collate, summarize, categorize, store and retrieve the search results.

Given the potential breadth of the review, the inclusion criteria for selection of papers was that children and young people's choice/decision-making in health services were either:

- A topic of interest was explored or the paper included the direct perspectives of children and young people (as opposed to those solely from the proxies' views, such as parents or professionals).
- A topic of interest was explored as part of a systematic/extended review.
- Part of a health intervention was evaluated, where choice was explicitly offered to children and young people.

Grey literature was subject to less rigid criteria and was included if it was deemed to be relevant and informative.

Definitions

Choice

As a concept, 'choice means the power to make decisions' (Rankin 2005). Appleby *et al.* (2003) outline a range of potential patient choices:

- Health-seeking behaviour (i.e. choice of lifestyle).
- Purchasing agent (although in the UK NHS this would require reorganization of the system).
- Whether to seek care or self-treat.
- Type of care, treatment, healthcare professional, accepting advice.
- Provider and time of treatment (i.e. public or private, local or not).

Participation

Choice is closely related to the concept of participation, defined as an individual's direct involvement in decision-making (Hill *et al.* 2004) and, in the case of children and young people, is based 'on a positive view of children's capabilities and recognise(s) the importance to children of the physical space and social contexts in which they lead their lives' (Hill *et al.* 2004).

Children and young people

For the purpose of this review, the term children and young people was used to refer to those under the age of 18 years, consistent with the definition used by the United Nations (UN 1989).

Search outcome

Many papers appeared in more than one database. Missing data were a common problem. Therefore, if the required information was not available from one source, an attempt was made to find alternative sources (CRD 2001). Only a minority of papers met the selection criteria. The final number of papers identified in each database is shown in Table 1. Each paper was repeatedly selected using a snowballing approach until saturation was reached. The references for the papers included in the scoping review can be obtained from the first author.

Quality appraisal

As with all scoping exercises, the aim was to map the extent and nature of the literature that currently existed in relation to the children and young people's choice, rather than to assess the quality of the individual studies identified. Therefore, an analysis of the strength of the included literature and an audit of the discarded studies were not performed.

Table 1 Number of papers identified

Database	No. papers
CINAHL (Cumulative Index to Nursing and Allied Health Literature)	536
Cochrane/York	14
Medline	622
PsychLIT	555
SSCI (Social Science Citation Index)	540
Social Care Online	128
Total	2405

Data abstraction

The included papers were read in full and descriptively summarized using a data extraction sheet in relation to their aim, health context, methods, participants, setting and results. Inclusion and exclusion criteria were established and each paper was examined to ascertain whether it met the inclusion criteria.

Synthesis

The evidence identified was read by both authors independently to identify first level concepts (Popay *et al.* 2006). These were subsequently analysed to produce a secondary level of conceptualization guided by the research questions. Similarities and contradictions were discussed by both researchers, which guided the final narrative and conclusions.

Results

Review limitations

While the results of the review were informative and presented an encouraging picture of collective choice in health service development, the number of studies was low, and most were small and descriptive (Table 1). It therefore remains unclear as to what extent results can be generalized to local or national concerns. Indeed, almost all participants were of school age (aged 6–18 years) and under-represented were the very young children, children and young people from Black and Minority Ethnic communities, looked after children, those with mental health problems, learning disabilities or life-limiting illnesses. There is also the possibility that the findings over-represent the views of the most articulate sections of society (Coad and Twycross 2006). This said, the findings do support the view that children and young people are able to give their views when given the opportunity.

What evidence is there that children and young people are being offered choice in health services?

It was clear that children and young people wanted to make decisions about their personal health care (Cavet & Sloper 2004a). However, there was little evidence about the choices they are actually offered. This echoes the findings of Cavet and Sloper (2004b), who reviewed decision-making in children with disabilities. There was, however, an associated body of literature examining consent and refusal in clinical management and medical research, generally against the backdrop of children's rights or high profile legal cases (Young *et al.* 2003, Neill 2005). This undoubtedly made a significant contribution to the choice agenda for children and young people and resulted in much discussion amongst healthcare professionals (Young *et al.* 2003, Larcher 2005, Neill 2005) and inclusion in practice guidelines (e.g. BMA 2003, Royal College of Paediatric and Child Health (RCPCH) 2005). Evaluative research examining children and young people's wider decision-making was scarce (Tates & Meeuwesen 2001, Bekker *et al.* 1999), but suggested that they had rarely been full partners in consultations, with most communication and decision-making occurring between parents and adult providers (Tates & Meeuwesen 2001, Young *et al.* 2003).

Children's and young people's collective choice about health service provision was predominantly discussed in relation to 'participation' or 'involvement' in the decision-making process (Laws 1998, Cohen & Emanuel 2000, Council for Disabled Children, 2000, Lightfoot & Sloper 2002a, 2002b, Sinclair *et al.* 2002, Boylan 2004, Cavet & Sloper 2004a, 2004b, Kirby 2004, McNeish 2005, RCPCH 2005).

Inpatient

Children and young people described the key aspects of hospital care as privacy, choice and competent, friendly staff (Kari *et al.* 1999, Carney *et al.* 2003, Battrick & Glasper 2004, Boylan 2004, Curtis *et al.* 2004, Moules *et al.* 2004, Coad & Coad 2008). In terms of children's and young people's views about hospital environments, there have been notable published literature such as L4A (1990); Anshen Dyer (1999); Russell-Johnson (2000); Carney *et al.* (2003); Coyne (2006) and Coad & Coad (2008). Overall, the key themes here were good communication, easy access to appropriate information, clear explanations of treatments, personnel with good interpersonal and technical skills, direct dealings with children and inclusion in decision-making. Specific groups were also highlighted, such as those with chronic illnesses, children with disabilities and adolescent care, in all of which limited choice and associated frustration was frequently reported (e.g. Needham 1997, Sartain *et al.* 2000, 2001, Norwich Union

2001, Horstman & Bradding 2002, F. Gibson, A. Richardson, S. Hey & M. Horstman, unpublished data).

Transitional care

Common issues in relation to transitional care from children to adult services included earlier planning, improved access to information and more ongoing advice for young people (Rabiee *et al.* 2005, Shaw *et al.* 2004a, 2004b). Whilst the involvement of young people in transition planning was seen as essential, many were not given adequate support to be able to contribute. Young people wanted developmentally appropriate care based on shared decision-making, continuity of care and wider access to information and community services. Shaw *et al.* (2004a, 2004b) also found that young people wanted individualized assessment of holistic needs and increased preparation for transfer to adult services.

Community care (including sexual health)

Dixon-Woods *et al.* (2002) highlighted that important dimensions for children and young people in community care included close monitoring of conditions, direct consultation, information-sharing and healthcare professionals who have specialist medical knowledge and are competent, sensitive and good communicators. Young people reported a lack of knowledge of services available from professionals (Turner 2003) and a lack of respect for specific teenage health concerns (Jacobson *et al.* 2000, Linnell 2002). This included sexual health concerns (French 2002, Nwokolo *et al.* 2002, Hayter 2005). Limited studies addressed respite care, although Minkes *et al.* (1994) found that, while most children and young people could access respite care services, choices could be variable.

Mental health (child and adolescent mental health services – CAMHS)

N. Dogra, P. Vostanis, H. Abuateya & N. Jewson, unpublished data, highlighted that children and young people wanted accessible community mental health services that were visible to them. This included wanting staff to respect them and listen to their concerns. General staff qualities desired included empathy, availability, confidence, calmness, self-control, protectiveness, genuine concern, good counselling skills, and a positive ethical stance (i.e. openness, trustworthiness, respect; Farnfield & Kaszap 1998, Laws 1998, Burston 2002, O'Herlihy *et al.* 2001, Stephens 2002, Street *et al.* 2005). In all the studies reviewed general themes of confidentiality, relevant information and the ability to make things happen emerged (Stephens 2002, Street *et al.* 2005).

Taken collectively, studies suggested that the quality of relationships with healthcare professionals is one of the most important aspects of care for children and young people,

evidenced through good communication skills and respect. The latter was demonstrated by providing choice in information needs and supporting shared decision-making. Other important provider characteristics were medical and technical competence and friendliness. Whilst process issues were less important, children and young people valued continuity, confidentiality and support during transition from children to adult services. Where the built environment was explored, children and young people stressed the importance of age-appropriate facilities, privacy and greater access to healthcare services that also acknowledged their existing commitments (e.g. school).

What are the barriers to offering choice to children and young people?

Barriers surrounding patient choice have been discussed by others (Appleby *et al.* 2003, Cavet & Sloper 2004a, 2004b, J. Coad & K. Shaw, unpublished data). Many of these barriers are judged to be in the public interest (e.g. control of dangerous drugs or restrictions on human cloning), or due to economic realities (e.g. offering treatments that are not cost-effective). Resource capacity is undoubtedly a key issue, and already in the UK there have been delays in implementing some of the technical infrastructure needed to support patient choice [National Audit Office (NAO) (2005)] and a lack of readiness amongst primary care organizations. Within the current framework in the UK it is likely that many choices for children will not be immediately realistic, and there may be some choices that children and young people cannot make independently. For example, hospital choice is likely to depend on the parent's access to transport. Some have also argued that patient choice may widen health inequalities, as there will be more constraints on the decisions that people in the lowest socioeconomic groups and rural areas can make (Burge *et al.* 2005).

In addition to resource issues, barriers also exist in relation to adults' concerns about offering choices to children and young people. Parents and professionals fear that 'children' do not have the capacity to make decisions, and worry that their choices will be irresponsible, self-centred or based on short-term gain (Hill *et al.* 2004). However, as stated in the *Mental Capacity Act* (2005): 'a person is not to be treated as unable to make a decision merely because he makes an unwise one decision'. In most cases, these fears were not necessarily founded; even very young children have been found to be capable of making competent and appropriate health decisions (Alderson & Montgomery 1996). This said, defining competence is contentious when children are very young or have mental health problems, cognitive impairment or learning disabilities (Moore *et al.* 1998, Bates & Meeuwesen 2001,

Alderson & Morrow 2005). However, regardless of legal debates, lack of competence does not remove the right to express a view. Thus, people cannot be considered unable to make a decision until all practical steps to help them do so have been exhausted, and lack of competence cannot be established solely in reference to a person's age, appearance or behaviour (*Mental Capacity Act* 2005). There is unlikely to be a blanket answer in terms of children's ages to the issue of when competence to make a choice can be assumed; as Masson (2004) notes, competence is directly related to the decisions to be taken and so will vary from one situation to the next.

This scoping review highlighted that offering choice is partially dependent upon the attitudes of healthcare professionals and their skills to manage a three-way relationship between themselves, the child and their parent(s). Unfortunately, while many hospital and community care deliverers in the UK have written strategies for patient and public involvement, Lightfoot and Sloper (2001, 2005) note that their systems to realize this are less well-developed and generally fail to identify children as 'service users'. Moreover, few of the reviewed documents paid significant attention to the changes required to an organization's infrastructure to support participation. This was further compounded by a lack of evaluative research focusing on staff-child-parent interactions (Bates & Meeuwesen 2001), particularly from the perspectives of children and young people (Crossley *et al.* 2005); this makes it very difficult to discern the most effective methods to support choice.

What can promote choice for children and young people?

Individual and collective choice inevitably requires sufficient resource capacity in the service, but as yet the need for this has not been globally mapped. An overall approach will require that organizations, and individuals in key positions, foster an inclusive approach that offers choice in flexible, appropriate ways and provides information and support tailored to individual needs (Save the Children 2000, Kirby & Bryson 2002, Cavet & Sloper 2004a). These approaches should not only take account of service user's health status, but also of their age, developmental stage, cognitive level, ethnicity, culture, gender and preferences for involvement. Indeed, the level of involvement found in the review varied along a continuum from full power-sharing and autonomy to tokenistic consultation (Shier 2001, Sinclair 2004, McNeish 2005). While some papers did advocate participation across all levels in the organization, this can be demanding for both children and organizations in terms of time and resources. It was generally agreed that children and young people should have an active role in decision-making, and that this should be based

on a genuine commitment to listen and act upon their views. Practical guides, which included a range of activities for participation for children and young people have been found to be useful (e.g. Morris 2002, Stafford *et al.* 2003, Wade & Badham 2003, National Evaluation of the Children's Fund 2005, Coad & Houston 2007). However, little guidance was found about the best ways to offer individual choice to children and young people in health and social care settings, and about support for ongoing decision-making.

Decision-making

There are obvious ethical and methodological implications of involving children and young people in decision-making about treatments and services. However, it is likely that children and young people will vary in their preferences about the degree of involvement in decision-making. Research with adult patients shows that most prefer a collaborative role to one that locates them either as a passive recipient of care or puts them in total control (Doherty & Doherty 2005), and this is probably also true for children and young people. Factors associated with decision-making, regardless of age, are likely to depend upon the context of the decision, the decision-maker(s) and the ways in which the decision is framed and supported. As yet, little is known about how these factors may influence the decision-making of children and young people or their parents and, while a number of strategies are suggested (Dixon-Woods *et al.* 1999, Kirby 2004, Larcher 2005), there is no firm evidence about what works best.

Information

Information has been highlighted as a fundamental prerequisite of choice for patients, including children, who 'have a particular need for information and support to participate in decisions which are sensitive to their age, stage of development, and balances confidentiality with the parents' need for information' (DH 2004). However, the need to provide parents with suitable information has also been highlighted (Beresford & Sloper 1999), as they are important sources of information for their children and young people. As Appleby *et al.* (2003) note, 'exercising choice demands little prior knowledge – but informed choice does'. Formal consent procedures in the UK (DH 2001b) require that children and young people and their parents are aware of the risks associated with the choices facing them, and in the review a number of supportive materials in a variety of languages were identified (J. Coad & K. Shaw, unpublished data). However, the availability of developmentally appropriate and culturally competent information about other aspects of choice was not well developed.

Staff training and support

Staff training and skills development were recurrently highlighted in the included papers as a key requirement (e.g. Balen *et al.* 2001, Kilgour 2002 and Claveirole (2005). Cohen and Emanuel (2000) asked children and young people to list important attributes that adults should have in order to facilitate participation, and these included reliability, respect, awareness of others, participation, and openness to learning. Hart and Chesson (1998) have also suggested a number of innovative ways to communicate with children and young people, including using puppets, drawings, photographs and videos.

Several authors have also recommended that adults need to support children and young people by acting as their advocates and training is required for this (Cavet & Sloper 2004a). Suggested roles have ranged from professional adult advocates or champions to peer mentoring. Access to independent mediation services may also be useful when there are discrepancies between the views of children and young people, their parents and healthcare professionals. Moreover, as Kirby *et al.* (2003) note, 'accepting responsibility for someone does not mean taking responsibility away from them'. Related to this is the notion of dedicated 'gatekeepers'. This concept is now 50 years old, but more recently has been taken to mean a person who decides what information/action passes through each level (gate) of interaction, of which there may be many. Gatekeepers usually provide, control, or even withhold, access to the child or young person. In most cases the role is that of direct gatekeeper (known as first level) and is fulfilled by a parent or carer, but it may be another person who acts as an indirect gatekeeper (second level) to the parents and carers. There are clearly overlapping considerations for both advocates and gatekeepers at both levels which, although interesting, are beyond the scope of this review.

Discussion

Over the last decade, there has been an increased emphasis globally on the active involvement and participation of patients (children, young people and adults) in decision-making processes about healthcare issues that affect them. In this scoping review of children and young people, a number of sound examples from the UK were drawn upon regarding individual and collective choice, particularly around service development. We found a large number of information, tool kits and policy documents for health service personnel, and thus we conclude that there is a good level of information and understanding about seeking views and giving choice to children and young people. However, there was less solid

What is already known about this topic

- Choice in health care is not a new concept and is important for all users of health and social care services.
- The importance of including children and young people in the choice agenda reflects the increasing acknowledgement that, individually and collectively, they are important consumers of health care in their own right.
- It is believed that giving citizens, including children and young people, real choice about services will drive up standards, improve efficiency and increase the level of patient-centred care.

What this paper adds

- Giving children and young people choice was viewed as a positive development in the United Kingdom healthcare services.
- Positive examples exist of children and young people being given choice but there has been less evaluative research about whether these choices were acted upon and resulted in services more responsive to their needs.
- Barriers to choice exist, including cost and resource implications, but a greater challenge may be changing professional attitudes to children and young people's choices.

evidence about the impact of children's and young people's choice in health care.

Whilst this scoping review was focused on UK literature, the issue of choice is being discussed internationally and most specifically this is seen in the developed countries. Examples from Canada (Stewart 2001, Villalon & Leclair 2004, the United States of America (Sharma & Finlay 2003); Australia (Boshoff *et al.* 2007); Sweden (Hallstron & Elander 2004) and Spain (Portero *et al.* 2002) highlight evidence of giving choice to children and young people in healthcare intervention programmes and service planning. Whilst innovative in their approaches, they give limited information about whether giving choice to children and young people has increased the responsiveness of children's health services. Given the limited impact indicated from this UK review, it is unlikely that the choice agenda will be significantly advanced until children and young people globally are seen as partners in health services, rather than as targets of interventions.

The review also highlighted that efforts to include the unvoiced and uninvolved are particularly warranted if services are to reflect the needs of all its users, including child and adolescent mental health services, hard-to-reach groups (i.e. asylum seekers, homeless people and travelling

people), people with disabilities, children under five years of age, Black and Minority Ethnic groups, and patients in hospice, palliative care and genetics settings. It may be that more choice is being given to children and young people than is evident in the literature. However, unless those involved in choice initiatives disseminate their results, the actual impact will be slow to spread.

Some of the challenges that surround children's and young people's choice involve the many contrasting epistemological positions related to their developmental processes. There is tendency for any debate about children's and young people's capacity to have choice to be based on markers related to age-specific qualities and less on aspects such as individual abilities, such as self-expression, decision-making abilities and interactions with others. As a result, further clarification is needed about the age of children, especially those under 6 years old, in relation to capacity to make decisions. Giving full choice thus requires a re-evaluation, based on developmental processes, of the ways in which children and young people individually and collectively prefer to make decisions. However, this may be difficult to achieve, as arguably giving children and young people choice in health and health care is emphatically not about empowering them to make decisions but rather about devolving adult power.

We thus concluded from the review that the practical implications of giving choice to children and young people in health care are still to be fully realized, both in the UK and internationally. We also suspect that there is widespread mixed understanding about what is meant by choice and how to go about achieving it. Consequently, a strong message from this scoping review is that serious consideration needs to be given to the ongoing training and support of healthcare personnel in techniques of eliciting and involving children and young people. We recommend that evaluating and disseminating such training is essential if this important change in healthcare services and policy is to be sustained.

Finally, whilst this scoping review may be limited in terms of depth, what was not clear to us was how offering choice had had an impact on health service delivery. Every effort was made to access published evidence of choice, but little was found. Thus, little hard evidence was found about the wider choices that children and young people want, the extent of choices currently offered, best practices to support choice or the outcomes of choice. This has international relevance in that the real extent to which choice is offered by individual healthcare professionals in the many different health services both in the UK and internationally will only be known through further research.

Conclusion

Whilst there are many positive examples of children and young people's consultation (both published and grey literature), solid evidence of their full participation was limited. More work is required to ensure that full participation is meaningful, effective and sustained. Dissemination of that work is thus essential.

It would also be useful to survey the long-term impact of offering choice to children and young people in healthcare services. One aspect of this work should be to explore, in more depth, a sample of case studies to evaluate the level of involvement of this group. To date, the focus has been on offering choice or its impact on a healthcare intervention, rather than evaluation of outcomes. Innovative ways should be sought to access 'hard-to-reach' or overlooked groups of children and young people for whom, by virtue of their needs and lifestyles, it is very challenging but not impossible to locate.

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Author contributions

JC was responsible for the study conception and design. JC and KS performed the data collection. JC and KS performed the data analysis. JC and KS were responsible for the drafting of the manuscript. JC made critical revisions to the paper for important intellectual content. JC obtained funding. KS provided administrative, technical or material support.

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