



METHODS OF INVOLVING DISABLED CHILDREN AND YOUNG PEOPLE IN CHILDREN'S SERVICES PLANNING

Kernohan, G., & Kernohan, G. A. (2002). *METHODS OF INVOLVING DISABLED CHILDREN AND YOUNG PEOPLE IN CHILDREN'S SERVICES PLANNING*. Southern Health & Social Care Trust.

[Link to publication record in Ulster University Research Portal](#)

Publication Status:

Published (in print/issue): 01/06/2002

Document Version

Publisher's PDF, also known as Version of record

General rights

Copyright for the publications made accessible via Ulster University's Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Ulster University's institutional repository that provides access to Ulster's research outputs. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact pure-support@ulster.ac.uk.

**‘METHODS OF INVOLVING
DISABLED CHILDREN AND YOUNG
PEOPLE IN
CHILDREN’S SERVICES
PLANNING’**

**A COLLABORATION BETWEEN SOUTHERN
AREA CHILDREN’S SERVICES PLANNING AND
THE UNIVERSITY OF ULSTER**

2002.

Foreword

This research, on how children and young people can become involved in the planning of services, is very much welcomed.

The Children's Services Planning (CSP) process is a new way of making sure that services are in place to meet the needs of children and young people, and involves staff from a range of agencies both statutory and voluntary. It also involves people from local communities and children and young people themselves.

In 2000, the CSP group looking at services for children and young people with a disability decided that a very important priority would be to find ways of involving children and young people with disabilities in the planning of services for the future. There were few existing examples of how this had been carried out elsewhere. The group decided that a piece of research was needed to help them find ways that work in involving young people. Fortunately, Professor George Kernohan of the University of Ulster was willing to enter into a partnership with the group to carry out this research.

This process, of a University being able to partner the Children's Services Planning process, in carrying out vital research, has been a very creative one, with important positive outcomes for both sides. People who are busy running services and thinking about how they should change in the future gained great benefit from the academic approach of Professor Kernohan and the young person's perspective from his young researcher,

Gayle. In return, the University of Ulster has benefited from working closely with those planning services in the community.

The Southern Area Children and Young People's Committee will be using this research to help involve children and young people, including those with a disability, in deciding what services should be in place in the future.

I would like to thank the members of the CSP Working Group, Professor Kernohan of the University of Ulster and Ms Gayle Kernohan for this excellent piece of work.

Brian Dornan

Chair, Southern Area Children and Young People's Committee
Director of Social Services, Southern Health & Social Services Board
Tower Hill, Armagh

June,2002

Contents	Page
Executive Summary	5
Acknowledgements	7
Chapter One – Background	8
<i>Introduction</i>	<i>8</i>
<i>Historical note</i>	<i>9</i>
<i>The new Assembly;</i>	<i>10</i>
<i>Benefit of user involvement</i>	<i>11</i>
<i>User participation in public policy</i>	<i>12</i>
<i>Participation by children and young people, Children (NI) Order</i>	<i>15</i>
<i>Why bother?</i>	<i>16</i>
<i>Where did we start?</i>	<i>17</i>
Chapter Two –Methods	18
Chapter Three – Findings	20
<i>General results</i>	<i>20</i>
<i>First Steps: Manipulation, Therapy & Informing</i>	<i>23</i>
<i>Step 4 Consultation</i>	<i>26</i>
<i>Step 5 Placation</i>	<i>27</i>
<i>Step 6 Partnership</i>	<i>29</i>
<i>Step 7 Delegated power</i>	<i>31</i>
<i>Step 8 Citizen control; controlling the process</i>	<i>32</i>
Chapter Four – Discussion	37
<i>Just do it!</i>	<i>37</i>
<i>Levels of involvement</i>	<i>38</i>
<i>Time; Trust; Get real!</i>	<i>39</i>
<i>User involvement across different sectors</i>	<i>40</i>
<i>Older users more than younger non-users</i>	<i>40</i>
<i>Needs assessment, Type of disability affects type of</i>	
<i>involvement; Communication</i>	<i>41</i>
<i>A matrix model</i>	<i>42</i>
Chapter Five – Conclusion	45
<i>User Involvement in this process, The methods of user</i>	
<i>involvement</i>	<i>45</i>
<i>Next steps</i>	<i>54</i>
Glossary	55
References	57

Executive Summary

There has been a discernible movement in recent years away from a paternalistic approach in the delivery of public services. Increasingly professionals and users share some responsibility for decisions about the service to be provided. The idea of partnership between professionals and clients is encouraged as this can improve outcome, contain care costs, raise satisfaction as well as improving the quality of research. To identify possible models of involvement of children and young people in services provided by health and social care, education and the voluntary sector, seven senior executives of a variety of statutory and voluntary agencies were interviewed by a 16 year old school-pupil using an agreed semi-structured schedule. Questions covered the services provided to children and young people and the associated planning process. Interviews were recorded and transcribed for qualitative analysis. The key issues uncovered were (a) time is needed for capacity-building; (b) a need to "get-real" (be pragmatic); (c) the public sector is not a leader in child participation, the voluntary sector has a more developed user-involvement approach; (d) start with involvement in planning for individual care, before becoming strategic; (e) use advocacy as appropriate; (f) older children who are frequent service users are more likely to respond than younger children who don't use the system; (g) needs assessment requires user participation; (h) different types of condition/disability require different approaches; (i) information from routine care can inform strategy; and (j) feedback is possible by survey, suggestion box or complaints system. Eighteen models of potential user involvement were identified, including focus groups, reference /user groups, pupil council, advocacy, and independent visitor and through the process of normal professional practice. To gain an understanding of the process, these

models were mapped onto a user involvement scale, first described by Arnstein in 1969, and then onto a two dimensional scale combining user involvement with communication level.

Promising methods of user involvement include:

- a. *“You tell-us, we put it all together”*. Integration of existing data from regular case reviews, especially for children looked after by the social services (Arnstein step 3),
- b. *“Helper”* or an advocate especially for younger children and the more disabled young person (Arnstein step 5), and
- c. *“You all decide”* in a peer-led focus group (Arnstein step 6 or 7).

By performing such multi-agency research, ideas for practice development can be found which have worked in another context. A further sharing of these ideas with young people is necessary in order to identify favoured approaches to user involvement in strategic planning.

Acknowledgements

The following members of the *Children and Young People with a Disability* Working Group of the Southern Area Children and Young People's Committee played a key part in the specification, review and guidance of the work.

Ms Angela McVeigh, Convenor (Southern Health & Social Services Board), Ms Ruth Nesbitt (Craigavon & Banbridge Health & Social Services Trust), Mr Aidan Rush (Armagh & Dungannon Health & Social Services Trust), Ms Marian Cully (Disability Action), Ms Ann Godfrey (Southern Health & Social Services Board)

The Southern Health & Social Services Board supported the preparation of this report.

A younger researcher, Miss Gayle Kernohan, ably supported the authors.

Special thanks to the managers and senior officers who agreed to be interviewed, read and corrected transcripts, and highlighted strengths and weaknesses in their approach to user involvement.

The Southern Health & Social Services Council made available their library of papers and reports.

Chapter One - Background

Introduction

“Children are our future”. Few would argue with this statement in the foreword to the Southern Area Children’s Services Plan 1999/2002. The Children's Services Planning process sets out to ensure that every child has the best possible start in life: by using ‘joined up thinking’ across the different agencies that provide services for children and young people; by ‘working smarter’ through better planning; and by creating ‘locality-sensitive services’. The plan set in train a multi-agency strategic planning process for services for vulnerable children and young people.

The first annual review of the plan set out progress up to April 2000. This recorded the size and complexity of the task: the first year was spent identifying sub-group membership across

agencies and breaking the work down into manageable tasks and beginning the planning work.

One aspect that has been selected for attention arose from the new social policy of user involvement. The three drivers of a user involvement policy are increasing consumerism, democracy and community development. Considering this policy context, from the outset it was considered very important that children and young people themselves are involved in the planning work. However, barriers to such involvement are considerable, especially for children and young people with disabilities. Therefore, this report will address models of user involvement applicable specifically to children and young people with disabilities.

All children have needs, wants and rights that should be met by statutory and voluntary agencies.

They can say and do some things for themselves. They certainly have views. This report is intended to contribute to the planning process so that more children have a better chance of getting the services that they need.

Historical note

Many types of service for children have been set up with an indirect rather than direct form of user involvement. Adults have set up services for children and young people using methods of adult participation (if any methods have been used at all). For example inviting young people to sit on a formal board or committee. Public services in particular were (and remain) accountable to the public through the democratic system, the lines of accountability being upward to commissioners and to government departments and onwards to parliament and the elected members of parliament or

now in Northern Ireland, our legislative assembly.

Significantly for the health & social services, in the 1970s, Health & Social Services Councils were introduced in Northern Ireland to represent the views of the public, including children and young people, to Health & Social Services Boards. Subsequently the health service has undergone management change following the Griffiths Report (1983). This led to a relationship between professionals and users more closely modelled on that more commonly seen between service providers and customers in the business sector, paving the way for innovations such as quality management, market research and a consumer focus. These were made visible mainly through staff appointments to a variety of posts of a business nature within middle management and through the

introduction of patient satisfaction surveys and other audit activities. The internal market, introduced in the 1990s, separated service providers from purchasers of services (Health and Social Services Boards) who were charged with the responsibility of purchasing health and social services according to the needs of their populations. A guidance document (Local Voices, 1992) specifically required purchasers to take account of the needs *and preferences* of local people, even acting as ‘champions of the people’.

The new Assembly

The new Northern Ireland Legislative Assembly with its Executive have continued to emphasise service user involvement in public health and in primary care (Department of Health, Social Services and Public Safety, 2000a,b). Recent consultative papers include

Investing for Health and Building the Way Forward in Primary Care promote user involvement:

Individuals, interest groups and local communities should be involved fully in decision-making on matters relating to health.

Investing for Health, 2000

It is proposed that new arrangements in primary care should: ... have a strong input from local communities and service users;

Building the Way Forward in Primary Care, 2000

These consultation documents display policies that will tend to cement user involvement into healthcare and pave the way for even further user involvement. Consultation has been described as being at the heart of Government’s commitment to

openness and inclusiveness. A web site provides links to the Central Consultation Register for Northern Ireland Departments at <http://www.consultationni.gov.uk/>

This includes useful direction on consultation with young people, such as “negotiate access”; “Get permission from the young people themselves”; “Advise the parents” and “Recognise the diversity of young people.” (Office of the First Minister and Deputy First Minister, 2001). The First Minister and Deputy First Minister announced on 29 January 2001 the intention of the Executive to establish the appointment of a Commissioner for Children as part of a wider children’s strategy. Consultation on the Commissioner role is at

<http://www.allchildrenni.com/>

Benefit of user involvement

A justification of increasing involvement from all sides can be found in the benefits to users of

all ages from all types of services. By enhancing user autonomy more control is possible and this may lead to more successful outcomes for users, whether such outcomes are in terms of social integration, general health status or user satisfaction. Partnership with users can contain costs and may raise satisfaction. Involving the user in research can also have similar positive impact.

A recent theme issue of the British Medical Journal, dedicated to a new partnership with patients, explored changes that have occurred in the structure of the doctor -- patient relationship and claimed:

Paternalism is endemic in the National Health Service. Benign and well intentioned it may be, but it has the effect of creating and maintaining an unhealthy dependency which is out of step with other currents in society.

They continue..

Assumptions that doctor (or nurse) knows best...should have no place in modern health care. The key to successful doctor-patient partnerships is therefore to recognise that patients are experts too.

Essentially, user involvement (in all public service planning) may allow services to be most closely aligned to users' needs and wants.

User participation in public policy

The World Health Organisation's Alma-Ata declaration said that people have a right and a duty to participate individually and collectively in the planning and implementation of their health care (WHO, 1978). This brief phrase from the declaration implies not only that people participate in their own care (individually), but also contribute to decision making on behalf of others (collectively). Clearly there is a range or scale of participation: from no involvement, through tokenism to full empowerment. The whole concept of user involvement has been growing in popularity and now stands enshrined in many strategic policy documents. Obeid (2000) lists a total of eight such documents, including *The new NHS. Modern. Dependable* (DoH, 1997). Obeid also cites ethical, legal and social reasons why we should incorporate the

idea of user participation in health care. Ethically, health professionals are guided by the principles of autonomy, humanity and self-determination. Legally, depending upon jurisdiction, the obtaining of consent is an imperative and some legal rights may impact on health. Socially, consumerism and the community development agenda have added further weight to the promotion of user involvement. In the context of Northern Ireland, public policy in health and social services also emphasises user involvement. The two main driving strategic documents of the Department of Health, Social Services and Public Safety regional strategy for health & social well-being 1997-2002 and Well into 2000 both emphasise and recommend user involvement. In addition, more recent strategy documents promote community involvement. For example, it is proposed that new arrangements

in primary care should have a strong input from local communities and service users. This would help promote accountability amongst primary care professionals to their local communities.

The NHS Executive further pressed patient involvement in care & treatment decisions in a paper “Patient Partnership” (1996) that promoted users in service development, monitoring and evaluation. However some uncertainty remains in how and to what extent the public may be involved. Uninformed opinion may conflict with overall strategy and be detrimental in terms of desired outcomes from health and social care services. There is a complex tension between service users and providers that user involvement seeks to mitigate.

- Each user presents with individualised needs and wants, yet service providers are in business to provide

services to groups or even populations: clearly some accommodation between group needs and individual needs is needed: user involvement may be able to assist in this accommodation.

- Both users and providers have knowledge and this is an important variable as knowledge is a key element in any professional service. Knowledge about the particular needs and wants lies mainly in the user, whilst experience and deep understanding lie mainly in the provider: both are required for successful delivery of services and solutions to user problems.
- On account of their needs, users may have resources of time and energy to apply, whilst providers often struggle to deliver services with limited resource. By involving users, their

resources may be more appropriately applied to the common good.

In addition to the role of involvement in diffusing tension between users and providers, citizens have a reasonable expectation to influence how and where public services are provided, and may have a reasonably objective viewpoint, including opinions about services for children.

A large number of existing methods have been used to capture public opinion about health and social care services. They range from the qualitative, in – depth interviews and group discussions to quantitative large-scale postal questionnaire, structured interviews and surveys. In addition less formal methods such as patient advocacy or representation may be more user-friendly (McIver 1991).

The Southern Health and Social Services Board published a User

Participation Policy which led those providing Health and Social Services to carry out Pilot Projects and begin building bridges between providers and adult users, through information and limited consultation (SHSSB, 1993). This laid the foundations for user involvement in the study area.

Participation by children and young people

In social care and in society generally, it has been argued that childhood has been afforded a relatively low status. Children with a disability may be further marginalised due to their increased vulnerability and powerlessness. As Alderson (1995) states

“.. much research with children is still adult-centric and dismissive of children..”

However, there have been major shifts in policy that promote the

active inclusion and participation of children in our society.

Children (NI) Order

In 1991 UK Government ratified the UN convention of the Rights of the Child and, in Northern Ireland, we have the Children (NI) Order (1995). This order requires partnership working with children and their families, in terms of planning individual care and planning of services for children in need.

Services providing care for children have been the subject of extensive legislation. Up until the enactment of the Children (1989) Act in England and Wales childcare law was expressed in a variety of pieces of legislation. The Children Act clarified and unified most law relating to the welfare of children, and strengthened the rights of children to participate in decisions about their care. The Children Act was followed by the

Children (NI) Order in 1995 in Northern Ireland. It lays down a number of guiding principles.

- The primary responsibility for upbringing of children normally rests with their families,
- Race, culture, language and religion are crucial influences on decision-making,
- **Relationships between service providers, children and families should be based on partnership and participation. Children should be involved as fully as possible,**
- The aim of substitute care should be to support families, not to disempower them. It should be arranged voluntarily rather than by force,
- Organisations should have clear policies for children,

including cross agency and multiprofessional working,

- Social intervention should be through a single legal channel and be rational, clear and co-ordinate private and public law.

The central underlying theme is that of working in partnership with children and families (Ryan, 1999). Children's Services Planning is a legislative responsibility stemming from an amendment to the Children Order, which aims to ensure that agencies provide services to children in need in a coherent way.

Why bother?

Three reasons for participation have been recently identified by Thomas (in Foley et al, 2001)

1. It is now widely accepted that children have a right to be heard and to have their views

taken into account in decisions that effect them.

2. Explaining properly, listening fully and acting accordingly can enhance self-confidence and engender feelings of control.
3. By involving users, the right decisions are more likely to be made more of the time.

Where did we start?

In the Southern Area of Northern Ireland, the Southern Health and Social Services Board has taken the lead in making arrangements for children's services strategic planning across eight groups: early years; children looked after; leaving care; young offenders; mental health; family support and child protection; young carers; and children and young people with a disability. With the development of working groups to take responsibility for certain aspects, the appropriate

professionals, community group members, carers and volunteers meet regularly to discuss the way forward. These people are all adults. It was clear that the Children's Services Planning process should involve children and young people in order to satisfy the Guidance on Children's Services Planning provided by Government as well as clear need for user input to the assessment of need. The question was how? This report provides a framework for thinking about involving the younger service user, together with a number of approaches to involvement. The Children's Services Planning *Children & Young People with a Disability Working Group* initiated the work, but the work is likely to have an impact on all the working groups.

Chapter Two - Methods

It was decided that a qualitative study based on a series of one-to-one interviews with strategic planners and/or chief executives would generate baseline data on the extent and type of service user involvement used at strategic level. Therefore during the summer of 2000 seven senior executives of a variety of statutory and voluntary agencies were interviewed by a 16 year-old school student using an agreed semi-structured schedule (see table 2.1). These seven organisations represented the majority of public and voluntary sector services available for children and young people in the catchment area of the SHSSB. Services included health and social services, education and voluntary sector organisations with a remit supporting disabled people. Following a brief introduction to the project by the adult researcher, the younger researcher posed questions.

These questions covered the services provided to children and the associated planning process. Interviews were recorded and transcribed for qualitative thematic analysis to identify common practices used to involve children and young people. To enhance content validity each transcript was returned to the interviewee for them to check for accuracy. In addition respondents were invited to highlight particular strengths and/or areas where improvements could be made, in terms of the involvement of children and young people in services that they use. The transcripts were seen and discussed by members of the multi-professional Children's Services Planning Working Group. The intention was that methods of involvement identified and confirmed in this way would be next presented to a group of young people to yield a prioritised list of participation methods.

Table 2.1. Schedule of questions posed by a 16 year-old interviewer to elicit models of user participation in Children's Services Planning.

- Can you describe briefly what services your organisation provides to children and young people?
- Can you tell me about your planning cycle or system?
- In what way do the views of children themselves influence –
 - ◆ services they receive themselves
 - ◆ strategic planning
- Are you generally happy with the extent of service-user involvement in your organisation?
- What is the current balance between professional decision making and user influence and what would be best practice? (How far should this go?)
- How do you think this balance might be measured and achieved?

Chapter Three - Findings

General results

Interviewees represented organisations that provided a range of services to children and young people from education, health and social services, and voluntary organisations. The services are set up in different ways under a variety of legal and organisation arrangements, leading to a range of approaches to user involvement. For example the voluntary organisations are very familiar with the concept of involving users. They tend to depend heavily on both volunteer and user participation at different levels, whilst, in some aspects of education and social care, services are delivered more according to closely defined guidelines and under statute than according to service user opinion.

Generally, respondents cited limited involvement of children and young people, but this did include several examples of involvement at an individual level. It was less common to find involvement at a strategic or service planning level. Most respondents described an annual planning cycle into which professional managers and planners made regular bids for resources, largely based on previous activity, but having definite scope for changes at the margin (small increases or decreases in service).

In describing the extent of involvement, the eight-step ladder of participation, originally described by Sherry Arnstein (1969), was used to structure the analysis (Figure 3.1). Whilst somewhat dated in terms of terminology, the original idea of a ladder proved to be helpful in exploring user involvement.

This ladder provided a conceptual model against which responses from participants could be classified. Each activity and response could be placed somewhere on the ladder. Alternatively, each step can be considered as a target and examples found to illustrate this position.

In an attempt to explore the model, the second approach is used below and summarised in tables 3.1-3.4. These illustrate the key methods observed, mapped against the Arnstein ladder of participation. A wide range of user involvement methods was identified, 16 discrete types plus two additional ways to manage the process. They are listed in tables 3.1-3.4 on pages 33-36.

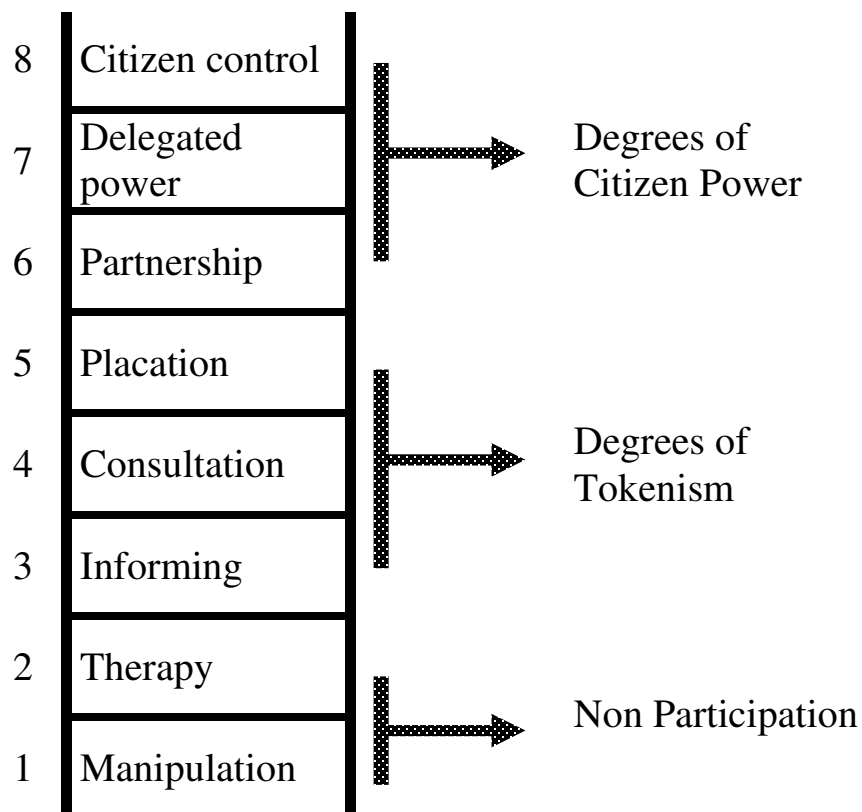


Fig. 3.1. Sherry R. Arnstein, writing in 1969 about citizen involvement in planning processes in the United States, described a ladder of participation. She was Director of the American Association of Colleges of Osteopathic Medicine. She served as Special Assistant to the Assistant Secretary of the Department of Health, Education and Welfare, where she planned a federal strategy to desegregate hospitals in USA. Her landmark analysis, published as a "Ladder of Citizen Participation", has been reprinted more than 80 times and has been translated into several foreign languages.

First Steps: “Manipulation and Therapy”

The first and second steps on the ladder are “manipulation” and “therapy”. These are non-participative and refer more to the activities of carers or service providers. The aim is to cure or educate the participants. The plan proposed by professionals is assumed to be best and the job of participation is merely to achieve public support by public relations. There are great intentions about what is best for people. Many agencies do publish annual reports and medium-term plans. In addition leaflets & booklets are common methods of informing people about public services and sometimes a “public notice” is placed in the press for dissemination of key information. In a similar way, public meetings are held to review activity and

inform the public. They appear on the second step on Arnstein’s ladder (table 3.1).

The complaints system is another frequently used method of acquiring service-user views. It may have a part in monitoring and moderation of extant services or even some new ideas for service development. It does not engage the user in the way that seems necessary for strategic service planning. Although by no means negative, these methods will not be considered in any further detail here.

Step 3 “Informing”

Sometimes seen as the first (and last!) step on the ladder of participation, informing is also a key prerequisite of any further user involvement. Informed service-users are able to relate to the service, understand it and gain satisfaction from its delivery. They may also increase

their uptake, at an earlier stage in their need, when more can often be achieved. In the long run, well-informed people are likely to make fewer demands on public services and may be able to share some responsibility for planning decisions that involve them. Furthermore higher satisfaction levels result (Various, 1999). In this study the voluntary sector placed emphasis on fully informing their target groups of users and parents, although this tended to be somewhat indirect as shown below.

Our business plan is informed and shaped indirectly, through our practitioners who are in day-day contact with young people.

Although indirect, this method of involving users as part of the routine service delivery was seen in several interview transcripts.

There is an informal professional network that exists as part of the staff's day-to-day work. .. The informal, invisible network does exist and contribute to the planning of services, particularly in levels of service to those with special needs. (N=3, table 3.1)

Having this embedded in practice was seen as being helpful.

A lot of user involvement takes place at the client level as clinicians interact with them in their daily work. (N=4, table 3.1)

In this case the information channel was two-way, with data informing the case planning process.

In another case:

an area of need is identified, operationally, as a bottom-up approach..

A well-informed user group is an important step. In one case this was achieved through:

posters, videos and tapes .. to encourage people how to get in contact

One manager described the challenge of user-informed planning, in a nutshell:

Effective communication with the public is difficult to achieve.

One respondent noted the link between user involvement and needs assessment: a prerequisite to the commissioning of health & social care services. Closer involvement of users in needs assessment would help address change:

.. work through needs assessment, to get to know the population. We do have a moving target, both needs and resources change dynamically. And further focussed involvement of users or non-users of certain ages should help us to cope with the dynamic.

These three methods of informing the user at Arnstein's ladder Step 3 are summarised in Table 3.1, N=3,4,5. These include indirect use of informal professional networks for information exchange, routine day-to-day clinical interaction and integration of individual needs information. This last idea

provides a ready-made source of rich data that is currently used for individual service planning. Within a statutory social work framework the potential for harnessing existing (group) needs was highlighted by one respondent who noted that

the LAC (Looked After Children) chair acts as a key informant to the planning process

Put simply, any child who is looked after by a Health and Social Services Trust on an overnight basis, is assessed under LAC regulations with two reviews per child per year. There is an independent LAC chairperson who chairs all the case meetings. Here, the informant was highlighting the possible role of this chairperson in the integration of individual needs into a more strategic view. Such integration of this data would provide a powerful indicator for future Children

Services Planning (N=5, table 3.1). Information is a core commodity in every public service and effective information systems are essential. Information from service users flows through carers and through service providers, in a kind of information pyramid (N=6, table 3.1).

Also at this “informing” level of involvement, many specific support groups operate in a self-help fashion, outside the formal planning process. However support groups exert some influence and offer significant help and encouragement (N=7, table 3.1)

Step 4 Consultation

It naturally becomes more difficult reach the user at a higher level of interaction that includes attitude surveys, neighbourhood meetings and public enquiries. For example, one respondent described the failure of postal consultation (N=8, table 3.2).

We sent out 90,000 leaflets in 1993 seeking a response to the acute service review, only 34 came back, so it's not easy to get the right message across.

Arnstein described consultation as a window dressing ritual, yet most people saw it as a valid step on the participation ladder.

Drafts of plans are produced and consultation is a key part.

In one case this is achieved through

.. a very elaborate committee structure to consult the people that we seek to represent.

(N=9, table 3.2)

Consultation has the advantage of snowballing, with “consultees” themselves becoming “consultants”:

We consult .. our own users and .. people we represent and also we facilitate other people in consulting

Step 5 Placation

Arnstein cites the co-option of carefully selected “safe” nominees onto committees. Several examples were found to fit the description on this rung of the ladder. A voluntary sector respondent reported:

We do have a younger person on our executive committee and we try to encourage their participation

Whilst in education, this step was illustrated as follows:

There is a youth subcommittee of the education committee. Young people are elected to this.

The above type of representation of users' views leaves decision control in the hands of the professional service providers, yet it does allow these decisions to be informed. In several circumstances this level of involvement included client advocacy (N=13, table 3.3):

Young person advocacy has been used recently to inform resettlement in housing following closure of a long-stay residential facility.

There were mixed feelings about advocacy, but on balance, it is likely that this type of participation has a valuable role to play:

with a nominated person to act as a rep .. the rep is only informed inasmuch as their own experience, and this is inevitably limited.

I think some service users are actually quite good advocates (and training is possible).

Participation is difficult in circumstances where the service user is a very young, pre-school age child, where the young person has severe communication difficulties or where no-one is motivated to participate, perhaps due to a short-term need for service. In these circumstances an adult (or another child) may be charged with the responsibility of standing-in for a group of such users. In this role they become experts in bridging the gap between the user group and the service provider group (N=10,11, table 3.2).

Some methods of health research depend on user involvement at this level. For example one-to-one interviews that seek out an in-depth understanding of issues (N=12, table 3.2).

Step 6 Partnership

Power over planning of services for children and young people resides mainly with professional service providers. However, in the voluntary sector it is common to share decision-making through joint committees.

we have always had an open forum .. for anybody who had an interest in learning disability .. it would be somebody's job to write down a set of objectives..

Special partnership with affiliated user/volunteer organisations also permits involvement at this level.

.. Gateway clubs (social clubs for people with learning disabilities) .. run by volunteers .. are an autonomous organisation but are affiliated to us and we provide support and training and advice..

The same interviewee mentioned a potentially useful initiative at this (partnership) level.

A new project (will gather) young peoples' views .. we invited young people to become involved and develop their ability to express their views ..

At an individual level, partnership between service provider and client is a recognised approach, where the care itself is individual:

Children are involved in their own care planning

But such partnership has a relationship with the capacity of the child to take this responsibility.

We need to draw the line somewhere in terms of age: about 16. Any younger age-involvement would seem difficult to manage.

And there was an important distinction made between involvement of young service users and involvement of non users:

From (age) 8 onward it would be possible, depending on their use of the service. Older children, who are frequent users may have more to say than younger children who don't.

A similar approach builds upon the idea of a focus group set up in parallel with an adult planning process to shadow a classic management group. The *Children and Young People with a Disability* sub group of Children's Services Planning uses a type of parallel focus group made up of voluntary and community groups working on disability issues, as well as parents of disabled children. This is described as a reference group (N=14, table 3.3).

At the same level, the legalistic idea of a "citizen's jury" allows a degree of partnership in decision making. Here a small number of options or issues are presented to a "jury" or panel who are charged with the responsibility of making an informed decision, or to rank the options put before it by "experts". This is sometimes set up as a kind of court case to consider presented evidence (N=15, table 3.3). This focus group is arranged as a jury to hear evidence from knowledgeable people who explore the main issues and answer questions.

The focus group, reference group and citizen's jury all permit an interaction between one or more researcher and a group of people for the purpose of collecting data. It appears in several guises in user involvement. By bringing several users together, it is assumed that valuable communication will be

facilitated. Either young able-bodied or disabled people may be trained as facilitators in the first type of focus group (N=16*, table 3.4). Users may need to be heavily supported in the activity. A second type of focus group may be organised in parallel with (and inform) a classical management committee (N=17*, table 3.4). This type of focus group is structured as a shadow of the “main” management committee and so may be seen as less important than it.

Step 7 Delegated power

Moving further up the ladder, the job of user involvement becomes increasingly demanding as people-power increases. The peer-led focus group is an effective method of involvement

with enough flexibility to allow the young people to choose their own arrangement. It is described as type 7 (delegated power) and has been used with able-bodied volunteers as leaders or facilitators. Discussions may be recorded, transcribed, computer analysed, moderated by peer-researchers. A significant period of time is needed for training and preparation of participants. This type of group work has been used by a joint Disability Action - Save the Children group to examine the educational experiences of young people with disabilities. They produced over 30 recommendations based upon group opinion (Educable, 2000), see N=16*, table 3.4). It was also suggested that some youth clubs have similar delegated power.

* types N=16,17 are placed on step 6 (Partnership) or step 7 (Delegated power) depending on the extent of professional control.

*in direction and activity,
youth councils and youth
forums may represent the
various clubs
(N=17*, table 3.4)*

Step 8 Citizen control

At the top of the ladder is citizen control (level 8). This final step, towards complete involvement is difficult to conceive in any area of Children's Services Planning. Although this top rung of the participation ladder is sometimes the target for user involvement, in this work, the desired level was agreed to be step 6: i.e. partnership. Citizen control of children services at a strategic level was not deemed appropriate. Whilst high on the ladder, methods at this level consist of adult solutions and normally require very high levels of communication and organisation.

Controlling the process

Examples of types of user participation have been identified along Arnstein's ladder, showing evidence of user involvement at several levels and present different degrees of power

sharing between users and service providers.

The arrangements for involvement take time and effort and the resources and expertise are not always available in-house. In the Health and Social Services sector (and elsewhere) the user involvement function may be out-sourced to an outside body. This body can then specialise in this activity using any of the methods already mentioned (N=18, table 3.4)

Similarly, where common user groups exist, the costs of the user-involvement function can be shared between two or more agencies (N=19, table 3.4).

8	Citizen control
7	Delegated power
6	Partnership
5	Placation
4	Consultation
3	Informing
2	Therapy
1	Manipulation

Table 3.1 On the lower rungs of the ladder, seven types of user involvement were identified to inform service planning.

N	Step on ladder	Method	Source	Comments	Name
1	2 Therapy	Routine day-to-day clinical interaction	Mainstay of much care	Case-specific, any user group	"Tell Doctor"
2	3 Therapy	Informal professional network	Variable in location & profession	One-sided, any user group	"You tell-us, we tell each other"
3	3 Informing	Publication of key information e.g. newspaper	Present to some extent everywhere	Suitable for adult user	"Put in on Paper"
4	3 Informing	Public meetings to review practice at a macro level	Most organisations are required to publish data	Mainly passive, indirectly involve all users	"Come to our meeting"
5	3 Informing	Integration of (existing) individual needs information.	Social services and education carry out regular case reviews. Could be brought together in a controlled way to inform planning.	Mainly for current issues, individualised and indirect, any user group	"You tell-us, we put it all together"
6	3 Informing	users' voices inform carers' who inform provider who inform the planning process	Already an implied function of most care delivered, though informal	Indirect - subject to other priorities, any user group	"You tell your mum + dad, they tell us"
7	3 Informing	Informal Support Groups	Any specific disability. E.g. in hearing impaired & autism	Weak influence, strong help, mainly for adults	"Mums' +Dads' group"

8	Citizen control
7	Delegated power
6	Partnership
5	Placation
4	Consultation
3	Informing
2	Therapy
1	Manipulation

Table 3.2. Two methods of user involvement were identified on step 4 (consultation) and five on step 5 (placation).

N	Step on ladder	Method	Source	Comments	Name
8	4 Consultation	Postal interview seeking opinions about planning options (quantitative)	Common research method, best if valid & reliable tool exists	Subject to bias + low response, superficial, adult users	"It's in the post"
9	4 Consultation	Committee meetings	Voluntary sector	Effective for adult users	"We meet Mums + Dads"
10	5 Placation	Independent visitors volunteer for a monitor role to concentrate (for example) on quality of experience of the child	Used successfully by MENCAP, including summer schemes	Indirect quality audit, suitable for children + young people	"Watcher"
11	5 Placation	Parental involvement in committee work provides the opportunity for advocacy	Very common in the education sector. Exists in Children's Services Planning reference group.	Mainly for current issues, individualised and indirectly involve all users	"We meet Mum + Dad"
12	5 Placation	Face to face interview seeking information in depth about perceptions and reasons (qualitative)	Quite common in health research	Direct but costly, not suitable for young children	"What do you think?"

8	Citizen control
7	Delegated power
6	Partnership
5	Placation
4	Consultation
3	Informing
2	Therapy
1	Manipulation

Table 3.3. Higher up the ladder of involvement, these types of user involvement were identified to inform service planning.

N	Step on ladder	Method	Source	Comments	Name
13	5 <i>Placation</i>	Advocacy in support of young people in expressing themselves, speaking on their behalf or presenting their case. Can include self-advocacy, peer-advocacy (disabled), peer-advocacy (child) or adult-advocacy. Implicit in some health and social care professionals' work	Fairly common in the voluntary sector.	<i>Mainly for current issues, individualised and indirect. Suitable for children.</i>	<i>"Helper"</i>
14	5 <i>Placation</i>	Reference group.	In place for carers to influence Children Services Planning.	<i>Indirect user voice, suit children of all ages.</i>	<i>"You meet in the other room"</i>
15	6 <i>Partnership</i>	May be organised to consider a single issue, as a citizens' jury, following a legalistic model	Recognised as effective in prospective views of issues	<i>Sophisticated, costly, for older children.</i>	<i>"We all decide together"</i>

8	Citizen control
7	Delegated power
6	Partnership
5	Placation
4	Consultation
3	Informing
2	Therapy
1	Manipulation

Table 3.4. Two arrangements were identified that were not actual types of involvement, rather useful ways of working with other organisations.

N	<i>Step on ladder</i>	Method	Source	<i>Comments</i>	<i>Name</i>
16	6 <i>Partnership</i> or 7 <i>Delegated Power</i>	Peer-led focus groups of young people with disabilities.	Voluntary sector. Also seen as a pupil council.	<i>Flexible, potentially effective for older children.</i>	<i>“You all decide</i>
17		Management Committee	Youth Club	<i>Adult style, suit older children.</i>	<i>“Some of you decide</i>
18	-	Sub-contract user involvement activity to a specialised watchdog organisation that uses any appropriate method	Health Boards have established Health Councils	<i>Builds external expertise, independent. Variable user group.</i>	<i>“On your behalf</i>
19	-	Where different agencies share the same user group, one user involvement method can work for both! Two for the price of one!	Gateway club evaluations inform MENCAP & vice versa.	<i>Dependent on close interworking. Variable user group.</i>	<i>“Two at once</i>

Chapter Four – Discussion

Just do it!

The top tip for successful participation from a directory of examples of service user involvement in supported housing is “Just do it!” People can sometimes be apprehensive about starting. It can help to first identify current practice to see where you are already making some progress. Then pick a task and start. Involvement will develop from that starting point (Keeble, 2000). This practical approach reflects the way this project has progressed: first identify current practice.

The different organisations have a range of different approaches. For example the voluntary sector has user involvement as a mainstay while the education board depends more on statute and achieving results through the school curricula. All the organisations have employed

user involvement to some extent, though most seem to dwell mainly upon immediate issues of direct impact on the participants, rather than involvement at a more strategic level. It is this more strategic planning for all (as opposed to planning for one) that the project sought to identify.

In keeping with the principles of the Children Act and Order it is clear that younger researchers should be employed to help formulate the questions, ask the questions and validate the results. The involvement of a young researcher from the outset is recognised as good practice in youth research (France, 2000) as it maintains an appropriate emphasis and relevance for younger people while ensuring that the language and content of methods, results and analysis are accessible. The young interviewer in this study was interested in the linkage between theory of participation (being a

good thing) and the variable practice encountered. She was able to ask and pursue basic simple questions and achieve clarity in the answers, where a more experienced person may have made the sessions complex or accepted more professional, managerial language.

Levels of involvement

The different levels of service user involvement have been described above using Arnstein's model, (see page 22) and in a simpler way by NSPCC (2000) as shown below (figure 2). These levels were evidenced in the current work, with most user involvement at the case level and less involvement at more strategic levels that include the current work on Children Services Planning. It became

clear that the top level identified by NSPCC can be divided into (1) involvement in monitoring and planning changes to existing services and (2) involvement at a strategic or policy level.

Individual Planning for Children in Northern Ireland was previously found to be in need of more focus and resources (Horgan & Sinclair, 1995). It is likely that these recommendations have seen some progress since publication and that an increase in this type of involvement may act as a useful backdrop to more strategic level involvement. However, it is difficult to imagine successful user involvement at strategic level, where individual case level involvement is weak or not used. Indeed there is an even more

- Planning groups at Board or Trust level
- Support and campaigning groups
- Individual case level

Fig. 2. Three levels of service user involvement identified by NSPCC (2000).

direct link between levels, as the information gained from a series of individual involvements may be integrated together to inform strategy. By building user involvement from the individual level (up through the three NSPCC levels, figure 2) involvement and partnership may be possible in a routine way as part of the care being delivered. Such a close link with practice would seem to offer an economic and long-lasting solution to the problem of capturing the user's voice.

Time

Agencies that have developed methods of involvement consistently report the time and effort that is required to make it happen. More specifically the exercise of capacity building (over a period of months) seemed to be a universal requirement for substantial involvement of users at the table with professional caregivers or managers.

Likewise further top tips for successful participation is "Give it time" and "Stick at it! It can be a long and frustrating process" (Keeble, 2000).

It is important to give children space to talk about issues that concern them, rather than just responding to adults' questions.

Trust

Children communicate best with people with whom they trust. It is important to be friendly, open and, above all, straight with children. We need to remember that body-language, tone of voice, facial expression and even style of dress can affect how children communicate. They need active support and encouragement. They should not be judged, criticised or put on the spot (Foley et al, 2001).

Get real!

It is clear that young people are sensitive to fashion and, to an extent, develop their own

communication and language. Involvement of children & young people will require sensitivity in both oral and written communication. For example avoidance of specialised, technical or subject-specific language. This can also help in multidisciplinary working.

Some younger people have an acute sense of ambition about what is possible: the agenda for change needs to be realistic. Indeed people of all ages will find it easier to relate to well-justified and achievable goals that are not too far out of sight or extreme.

User involvement across different sectors

User involvement is a variable concept with different examples across different agencies and sectors. It became clear that examples of good practice in one sector might well serve as options for other agencies to adapt and adopt. In particular,

voluntary agencies have a number of methods that may be useful in this context. Their use of focus groups is a particular example. Another semi-formal method especially for situations where communication is difficult is advocacy.

Older users more than younger non-users

There are two important variables that may influence involvement of children and young people. As a child develops he/she changes in the appreciation of others, as opposed to the appreciation of self and selfish needs. Thus age is a key factor, particularly where a wider perspective is required. In general terms an older child has better-developed communication skills and possesses more maturity in the appreciation of the roles and tasks of health and social care, education and other services made available to them. Secondly, a child who is a more

frequent user of a service may have more capacity to contribute to planning that service. Taken together, it is clear that older service users will have more to say than younger non-users.

Needs assessment

At many levels of service provision (community, Trust, Board), formal needs-assessment methods are used to help influence service delivery and change. Where this activity is occurring there is the possibility of user involvement. Indeed the methods of needs-assessment and user involvement overlap to a significant extent.

Type of disability affects type of involvement

Where we require the disabled user's voice, it is clear that the nature of the disability is likely to influence the process. The ability to acquire opinions and views is affected by the nature of communication and other

difficulties presented by the child's disability. Those with a physical disability may present different challenges from those with psychological or learning disability, each different from the situation where the child has more complex needs. It is also worth noting the crucial importance of the level of communication skill of those seeking to elicit opinions or input from children and young people. Therefore we may not expect a single method to be capable of answering all questions. Children and young people with a disability are not all the same. Barriers of inaccessible venues, as well as lack of suitable modes of communication necessary to acquire their opinions and views, need to be addressed proactively as access and communication will underpin all other rights.

Communication

A broad and flexible definition of communication is important

when working with disabled children and young people. Attention must be paid to the various communication channels: speech, sign, symbols, body language, facial expression, gesture, behaviour, art, photographs, objects of reference, games, drawing and playing. *Talking* may not be the best or only channel. (Marchant, 2001). Many children find it boring to sit and talk. The fact that serious matters are being discussed should mean that everyone has to be “po-faced”! If decision-making processes are made more enjoyable, they are likely to stay involved.

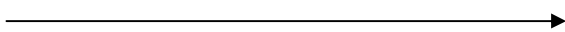
A Matrix Model

Arnstein’s ladder of user involvement provides a useful framework against which groups of people involved in Children’s Services Planning can plot the current position and thereby set achievable targets for enhanced involvement. However, it has

become clear that the nature of any disability will influence the choice of method. To explore this further another dimension is proposed – communication level of the user group. Respondents confirmed that older users would have more to say than their younger counterparts. Table 4.1 presents a matrix model combining Arnstein’s eight steps on the vertical dimension with a scale of communication level on the horizontal dimension. This is an over simplification of a complex issue combining two key communication influences of developmental age and developmental disability into a single dimension. In addition some user involvement methods make use of advocacy to a greater or less extent. One may assume that advocacy may be introduced where the child or young person is unable to use that method (fully). Essentially, we have included the matrix for scaling user involvement so that

readers can appreciate that user involvement of children, though complex and multi-factorial, can be simplified into working models having dimensions to guide the further development of this topic. It is not intended to be a finished agenda.

Table 4.1. Matrix for placement of user involvement on a scale of level of participation, recognising the independent factor of capacity to participate and communicate fully, itself dependent on both developmental age and disability. Subjective placement of types on the matrix highlights potential gaps at the higher levels of involvement of children and young people. Showing index numbers from tables 3.1-3.4.

	Disabled		No disability
	Suitable for Children	Advocacy Methods	Suitable for Adults
	Communication level (combines age & disability)		
	None  Full		
↑	Citizen control		
	Delegated power		
	Partner-ship		
	Placation		
	Consultation		
	Informing		
	Therapy		
	Manipulation		

Chapter Five - Conclusion

Use Involvement in this process.

Having successfully employed a young person to deal with the interviews of executives of public service provider organisations, the project has to a limited extent “practised what it preached”. However, the methods discovered by this approach could be best validated by wider involvement with the target user groups. What might seem useful to a group of professionals may have little relevance to the young people themselves. The next stage would therefore involve a convenient sample of young people with a range of disabilities. They would be presented with a range of methods and be given the chance to select which methods they prefer. It would seem necessary and appropriate to recruit a small group of young people to help in

making the arrangements for this – based upon clear illustration of the different choices to be made. Further work on the development of suitable illustrations (or vignettes) would be needed.

The methods of user involvement

The research identified a set of 18 methods of which two were very similar and one was essentially an external approach, where an outside agency does the involvement work. Each method is summarised in following tables, (Tables 5.1- 5.18) each giving a basic description of the method with the pros and cons of each. Where possible a note of how the method would begin is included.

To take the agenda forward, it is possible to use the ladder model of Arnstein again. The first steps to involvement are information gathering and consultation.

One method which seems to show particular promise is, the integration of existing data from regular case reviews (*“You tell-us, we put it all together”*, table 5.5). This approach seems to be most likely to succeed given that the data already exists. In any circumstances where individual responses, opinions, wants and needs are recorded for individuals, it is possible to draw data together to identify a summary of the main issues.

A second is the *“Helper”* advocacy route to involvement. (Table 5.13). It is likely that younger children and the more disabled young person will benefit most from this approach. In some services advocacy is a well-developed approach towards professional representation of users’ views and experiences. In fact it is central to any discussion of involvement and empowerment. Beresford and

Croft (1993) describe five types of advocacy:

- Self-advocacy, where people are facilitated to speak for themselves.
- Legal advocacy, people with a legal training assist in exercising or defending rights
- Professional advocacy, people with a special training help with finance, housing, social services and general welfare issues
- Lay or citizen advocacy where a valued citizen (unpaid and independent of service providers) creates a relationship with those who are at risk of social exclusion. In this way they bring that person’s concerns into the circles of influence, as if they were their own. (O’Brien, 1987)
- Peer advocacy, where people advocate for others with similar experience.

This has links with the peer-led focus group ("*You all decide*", table 5.16) that was found to be successful in the voluntary sector.

It is recommended that these three methods of user involvement should be tested and evaluated over a 12-month period.

The evaluation would audit the extent that children & young people felt they were involved in their care and assess the target extent to which user involvement can reach, in terms of Arnstein's ladder depending on their disability and desire to participate.

Table 5.1. Summary of *“Tell Doctor”*

<i>Basic description</i>	This method emphasises the need to explicitly gather and record users’ opinions throughout routine service delivery.
<i>Pros</i>	Easy and cheap to implement, already happening to a large extent.
<i>Cons</i>	Places an extra burden on service providers. Passive, indirect involvement of children in planning.
<i>Begin by</i>	Identifying this work within service-level agreements.

Table 5.2. Summary of *“You tell-us, we tell each other”*

<i>Basic description</i>	Informally draw together professional service providers’ views about ways that children are currently involved in their own care and in service plans
<i>Pros</i>	Provides a baseline, snap-shot of current state of involvement. Describes this current study, convenient sample, informs key decision-makers
<i>Cons</i>	Passive and doesn’t involve children, other than as an interviewer.
<i>Begin by</i>	(Already begun, describes the approach of this research)

Table 5.3. Summary of *“Put in on Paper”*

<i>Basic description</i>	Information about existing and new services and changes are published in a newspaper
<i>Pros</i>	Easy, relatively cost-effective method of reaching a wide readership.
<i>Cons</i>	Passive, non-specific, non-interactive and doesn’t involve children
<i>Begin by</i>	(Already in common practice)

Table 5.4. Summary of *“Come to our meeting”*

<i>Basic description</i>	Everyone is invited to a formal meeting, with a chairman who goes through an agenda of specific issues to be discussed. Someone will take notes
<i>Pros</i>	Easy, relatively cost-effective method of reaching an audience of interested people. Includes service-users, carers and other non-users.
<i>Cons</i>	Only some people will speak up. Passive and non-interactive for others. Might involve older children
<i>Begin by</i>	(Already in common practice for annual reports and special events)

Table 5.5. Summary of *“You tell-us, we put it all together”*

<i>Basic description</i>	Draw together users’ views from existing data sets by looking for common messages in records and files of children who are in receipt of health or social services.
<i>Pros</i>	Easy and cheap to implement.
<i>Cons</i>	Passive, doesn’t actively involve children.
<i>Begin by</i>	Identifying “who, what, where, when, how”

Table 5.6. Summary of *“You tell your “mum + dad”, they tell us”*

<i>Basic description</i>	The child’s main carer could receive training in advocacy and are invited to speak for the child, to planning people.
<i>Pros</i>	Utilises highly motivated volunteers
<i>Cons</i>	Carer only concerned with a single service user. Need to manage possible tension between carer and user. could lead to unrealistic expectations
<i>Begin by</i>	(Already common in some areas)

Table 5.7. Summary of “*Mums’ +Dads’*” group”

<i>Basic description</i>	Small groups of carers and some users meet to agree issues about the service delivery
<i>Pros</i>	Easy to implement, already happening to some extent. People can support each other
<i>Cons</i>	Assumes that a consensus is possible and representative
<i>Begin by</i>	Identifying & describing good practice.

Table 5.8. Summary of “*It’s in the post*”

<i>Basic description</i>	A published satisfaction questionnaire is sent to a sample of users and carers to collect views about service delivery
<i>Pros</i>	Convenient to implement, could involve children, favoured by researchers
<i>Cons</i>	Sample may exclude issues and special cases. Difficult questions may be ignored.
<i>Begin by</i>	Identifying questionnaire & sample

Table 5.9. Summary of “*We meet Mums + Dads*”

<i>Basic description</i>	A very small number of carers and children are invited to attend service planning committee meetings
<i>Pros</i>	Utilises (and promotes transparency of) existing management system of meetings, likely to suit service providers
<i>Cons</i>	Users & carers require confidence- & capacity-building, may not suit children, weak representation
<i>Begin by</i>	Already common for professionals

Table 5.10. Summary of *“Watcher”*

<i>Basic description</i>	A volunteer creates a relationship with the children, bringing their concerns into the open. A type of advocacy using an independent visitor.
<i>Pros</i>	The outsider may bring objectivity
<i>Cons</i>	Visitor needs training
<i>Begin by</i>	Identifying & describe good practice.

Table 5.11. Summary of *“We meet Mum + Dad”*

<i>Basic description</i>	Similar to N=9, above with parents on committees
<i>Pros</i>	
<i>Cons</i>	
<i>Begin by</i>	

Table 5.12. Summary of *“What do you think?”*

<i>Basic description</i>	A small number of carers and children are invited to participate in semi-structured face-to-face interviews
<i>Pros</i>	Established method, high focus on quality of service provision
<i>Cons</i>	Cost (time consuming)
<i>Begin by</i>	Identify/recruit interviewer & agree interview schedule

Table 5.13. Summary of *“Helper”*

<i>Basic description</i>	Two types of <i>Helper</i> or advocate were identified. <ul style="list-style-type: none">• Self-advocacy, children are facilitated to speak for themselves and others with similar experience• Professional advocacy, people with a special training help with finance, housing, social services and general welfare issues.
<i>Pros</i>	Integrates with existing management quite well
<i>Cons</i>	A significant training
<i>Begin by</i>	Identifying & describing good practice, then organise advocacy training

Table 5.14. Summary of *“You meet in the other room”*

<i>Basic description</i>	A reference group made up mainly of carers and users is set up to consider children services planning in parallel with the professional committee with a clear remit
<i>Pros</i>	Builds on existing approach while giving voice to carers’ concerns
<i>Cons</i>	Method may not suit children as much as adults
<i>Begin by</i>	Already started for this CSP group.

Tables 5.15. Summary of *“We all decide together”*

<i>Basic description</i>	A number of carers and children are invited to participate in a single focussed meeting to inform decision-making
<i>Pros</i>	Established method, high focus on a set agenda, rapid
<i>Cons</i>	Cost, may miss user issues
<i>Begin by</i>	Identify/recruit a professional co-ordinator identify sample of users and carers. Then agree a focus and start discussion.

Table 5.16. Summary of *“You all decide”*

<i>Basic description</i>	Similar to above (N=15) with a peer-led focus group having control over agenda in the hands of carers and children
<i>Pros</i>	Agenda may not match remit of service provider
<i>Cons</i>	High costs
<i>Begin by</i>	Identifying & recruiting a lay co-ordinator, identify sample of users & carers

Table 5.17. Summary of *“Some of you decide”*

<i>Basic description</i>	A management committee made up mainly of carers and users is set up to consider children services planning
<i>Pros</i>	High degree of involvement
<i>Cons</i>	Method may not suit children
<i>Begin by</i>	Identify sample of users to sit on the committee, train them

Table 5.18. Summary of *“On your behalf”*

<i>Basic description</i>	Subcontract involvement function to an outside organisation
<i>Pros</i>	Brings outside expertise to bear, short-circuits set-up period
<i>Cons</i>	Fails to build local capacity
<i>Begin by</i>	Writing a tender document

Next steps

Eight elements that go towards effective involvement have been listed by Beresford & Croft, (1993). These are: resources, information, training, research & evaluation, equal access & opportunities, forums and structures for involvement, language and advocacy.

Methods of user involvement, when validated by a user group will be ready to implement in practice. Not all methods will be suitable for involvement at a strategic level. Different methods will be needed for different user groups - depending on their age and nature of disability. However, it will be possible to make educated and informed decisions. Given the nature of the problem, the initial task is the selection of user involvement methods suitable for delivering reliable opinions and decisions to the Children's Services Planning process on an ongoing basis from service users with a range of disabilities.

Glossary

Autonomy. Independence. The ability to decide things for yourself.

Capacity-building. Exercises to teach a group of people how to speak-up and decide things for themselves and engage in consultations, partnerships and planning processes.

Children Service Plan. A way of working that sets out to ensure that every child has the best possible start in life: by using 'joined up thinking' across the different agencies that provide services for children and young people; by 'working smarter' through better planning; and by creating 'locality-sensitive services'.

Commodity. Product or service.

Conceptual. Describes an issue that only exists as an idea or theory.

Dissemination. Giving out or spreading.

Endemic. Widespread and common

Jurisdiction. Area in which there is a common authority or official power.

Locality-sensitive services. Things are done for people in a way that takes account of where they live and what other services are available there.

Marginalised. Made to feel insignificant or less important.

Multidisciplinary. A way of working together that involves several different people, such as doctors, nurses and teachers.

Multifactorial. A complicated issue that is influenced by several factors.

Paternalistic, paternalism. A way of working that keeps most of the authority and power with the man in charge.

Placation. One of the steps on the ladder of participation, where people feel they are being involved in the decision-making process.

Prerequisite. Something that is needed before something else can be done. A prerequisite to the second rung on the ladder is being on the first rung. Sometimes we say we have to walk before we can run!

Qualitative. This describes a research method that takes account of meanings and helps us to understand things by talking about them.

Quantitative. A type of research that counts people and measures items.

Unified. Brought together into a common place, from different places.

Validated. Checked as true, by doing things in more than one way.

References

- Arnstein, S.R. (1969) A Ladder of Citizen Participation, *Journal of the American Institute of Planners*. 35 (4) 216-24.
- Beresford, P., Croft, S, (1993) *Citizen involvement*, Basingstoke; Macmillan.
- Department of Health (1997) *The new NHS modern. Dependable*, London; HMSO.
- Department of Health, Social Services and Public Safety (2000) *Investing for Health*, Belfast; HMSO.
- Department of Health, Social Services and Public Safety (2000) *Building the Way Forward in Primary Care*, Belfast; HMSO.
- Educable (2000) *No Choice: No Chance*. Belfast: Save the Children.
- Foley, P., Roche, J., Tucker, S. (eds.) (2001) *Children in Society, Contemporary Theory, Policy and Practice*. Palgrave, Basingstoke.
- France, A. (2000) *Youth researching youth: The Triumph and Success peer research project*. National Youth Agency.
- Horgan G., Sinclair, R. *Planning for Children in Care in Northern Ireland*. National Children's Bureau Enterprises, London.
- Keeble, M. (2000) "Just Do It!" A Directory of examples of service user involvement in supported housing. The Housing Corporation, London.
- NSPCC Consultancy Services (2000) *Review of Services for Children with a Disability*. Southern Health & Social Services Board, Armagh.
- Obeid, A. (2000) Perceptions of user participation in health care. *JCN*, 14 (4).
- O'Brien, J. (1987) *Learning from Citizen Advocacy Programs, Georgia, USA*, Georgia Advocacy Office.
- Office of the First Minister and Deputy First Minister (2001) *Guide to Consultation Methods for Northern Ireland Public Authorities*, Belfast; HMSO.
- Parahoo, A.K. (1997) *Nursing Research- Principles, Process and Issues*. Macmillan, London,
- Ryan, M. (1999) *The Children Act 1989: Putting it into Practice (2nd ed.)*. Ashgate, Aldershot.
- Southern Health and Social Services Board (1993) *User Participation Policy*. Armagh.
- Various (1999) Embracing patient partnerships *Br Med J* 319 (7212).
<http://www.bmj.com/content/vol319/issue7212/>
- World Health Organization (1978). *Primary Health Care: international conference on primary health care, Alma Atla, USSR*. World Health Organisation in conjunction with United Nations Children's Fund.
<http://www.who.int/home-page/>

Professor of Health Research
Institute of postgraduate Medical & Health Sciences &
School of Health Sciences
University of Ulster at Jordanstown
NEWTOWNABBEY BT37 0QB
E-mail wg.kernohan@ulst.ac.uk