

CONSULTING WITH CHILDREN WITH DISABILITIES AS SERVICE USERS:

PRACTICAL AND METHODOLOGICAL CONSIDERATIONS

Executive Summary



**SOCIAL SERVICES
INSPECTORATE**



Trinity College Dublin

children's research centre
research for children & young people

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Prepared for the Social Services Inspectorate

December 2006

Introduction

The present Review was undertaken in response to a request from the Social Services Inspectorate (SSI) to initiate a process which would assist them to prepare for the inspection of residential centres for children with a disability in Ireland and help them become aware that there may be specific challenges in working with children with different types of disabilities. In achieving these aims, the Review may also be seen as contributing to the realization of the goals of the National Children's Strategy in Ireland (2000) - giving children a voice, finding ways of understanding children's lives and needs, and assisting with the provision of appropriate services for children.

The Social Services Inspectorate has been inspecting residential facilities for children for some years and a series of information leaflets has been designed by them (see www.issi.ie/inspection) to inform all those involved about what is entailed in the process. It is part of the inspection ethos to seek the views of those who use the services that are being inspected. In seeking to broaden their remit to include the inspection of residential units that care for children with disabilities, the Department of Health and Children started work in 2004 on progressing the legislative changes required. In addition to this preparatory work, the NDA carried out a round of inspections of centres for children with disabilities but without any regulatory remit, in order to pilot draft standards. In addition, the SSI commissioned the Health Research Board (HRB) to compile a directory of full-time, respite and

holiday residential placements for children with disabilities. The present Review constitutes a further contributory factor to this process.

Aims of the Review

- To review the literature on the viability (+ validity and reliability) of research where the main informants are children with different disabilities, with specific reference to issues of intellectual disability; this was achieved.
- To review other activities such as inspections or monitoring visits, investigation of complaints and police inquiries where the views of children with disabilities are elicited to inform the findings. Reports of these were found in UK publications, but despite extensive searching and enquiries we were unable to locate published or recorded evidence of such activities in Ireland.
- To provide a summary of materials (tools, tapes, videos etc) developed with a proven record in the area; this was achieved.
- To offer advice on how the SSI's current methods of involving children and hearing their views might need to be adapted with children with disabilities.

Background

The development and application of methodologies for consulting with children with disabilities should be based on an understanding of two underlying contextual factors: a rationale for consulting with children and an awareness of and sensitivity towards the existence of models of disability.

Rationale for consulting with children

With the widespread ratification of the United Nations Convention of the Rights of the Child (1989) (UNCRC - ratified by Ireland in 1992) there has been increasing recognition of the rights of children. Lansdown (1996) reminds us that the UNCRC challenges the traditional assumptions about the status of children in society and recognises children's rights not only to survival, development and protection, but also to basic civil rights: the right to freedom of expression, religion, conscience, association, information, physical integrity and to participation in decisions on matters of concern to them. Involving and consulting children and young people is gradually gaining acceptance and numerous publications have been produced to assist in this process.

Models of disability

Models of disability will influence the approach taken by individuals working in the field. The medical model focuses on the individual concerned and may result in individuals being represented by what they lack rather than as who they are; this model is seen as reinforcing rather than as challenging social exclusion. The social model, on the other hand, focuses on society and its disabling structures

and encourages the exploration of ways in which it could be more inclusive. The International Classification of Functioning (ICF) proposes a 'rights-based' approach and aims to include all the dimensions of disabled people's experiences - bodily, psychological, cultural, social, political - rather than claiming that disability is either medical or social. It proposes that everyone is impaired or disabled in some way, but that society is more adapted towards the needs of some than of others. The extent to which individuals are enabled to participate in society is seen as crucial in this alternative model.

Consulting with children and young people with disabilities

Internationally, the voices of children with disabilities were largely absent from research on children with disabilities until comparatively recently. A review undertaken in 1994 in the UK found no studies giving the perspectives of children with disabilities (Shakespeare and Watson, 1998). An increasing volume of research has been reported since that time, both in Ireland and in the UK (referenced in the full text of the Review). As well as research findings, there has been an increasing number of publications giving guidelines for assisting and supporting the participation of children and young people with and without disabilities in any consultation or research process (see full text).

¹ The full version of this Review is available on www.issii.ie and www.tcd.ie/childrensresearchcentre/

However, the extent to which children and young people with disabilities have been consulted by authorities in Ireland about anything appears to be meagre. While a number of agencies contacted in the course of this Review were currently thinking about consulting with children and young people with disabilities, only the ISPCC had actually had some experience of it and was in the process of developing some methodologies. The work of the SSI in consulting with this group will therefore be groundbreaking and should serve as a model for other agencies.

Qualities of desired outcomes of consultations

Where the aim is to access the views of children and to an even greater extent where the children have disabilities, considerable skill is called for in order to ensure that this aim is achieved ethically and professionally. Lewis (2002) elucidated three outcomes which should be striven for by those seeking to elicit the views of children with {learning or other} disabilities. These are:

- Authenticity - this requires the consulter to check that the views expressed are fair and representative - responses should be checked across contexts and strategies;
- Validity or credibility - which demands that the consulter checks that their interpretations of the views expressed are correct;

- Reliability or trustworthiness - that the responses are typical of what the person believes; this is of particular concern where communication needs to be facilitated and sustained by clarifying and confirming meanings, whether or not additional methods are used to support the interview. Issues around reliability include suggestibility, compliance, misinformation, distortion of events and need for faithful and accurate recording.

What needs to be taken into account in planning a consultation with children and young people with disabilities?

The process of supporting participation by children with disabilities in consultation/research is described by most writers as 'challenging'. **Basic considerations** in relation to the competence of the child with disabilities which must be taken into account include obvious factors such as:

- the developmental status and chronological age of the children,
- their age and capacity,
- the nature and severity of their impairment - not simply the category of impairment, but how it affects their communication,
- what support is needed to assist communication - for example are the children nervous, timid, or alternatively, energised in the presence of a stranger? Will this impede communication?

In addition the inspector should consider:

- the state of ongoing physical health of the child,
- the implications for the style, intensity and frequency of the interactions with the inspector, and
- the nature of the communication between participant and inspector.

The initial assessment of these elements should assist in making decisions about the structure of the visits and in particular in relation to the following aspects:

- not having tight deadlines,
- having the possibility of doing more than one visit,
- children's involvement in
 - writing, and
 - structuring the information schedule.

Additional intrinsic factors

In addition to the factors which could be seen as being directly related to the child's impairment there are other factors which are more 'intrinsic' in nature and which will have a bearing on the degree of participation elicited.

These include:

- an understanding of the nature of children's thinking about the world,
- their understanding of what is going on, and
- their ability to reflect on their experience.

In addition it would be helpful to have:

- knowledge of the kinds of experiences they have had in collaborating and being consulted,
- an understanding of the convention of compliance and of deferring to authority figures,
- some information about the constructs held by the children in relation to:
 - the consultation itself,
 - its aims,

- *and whether* they themselves or other people in the future are likely to benefit.

As in any fact-gathering exercise it would be useful to have objective data available to triangulate with observations and conversations.

Supports

Inspectors should be skilled in maximising self-esteem and self-confidence so that the child is empowered to contribute as fully as possible. They should know how to enhance the potential of children to communicate while showing respect for the child and reinforcing his or her motivation to participate. They should be aware of biases within themselves - perhaps an inability to 'hear' the child where the adult's concept of the world and relationships is being challenged, - and aware too of their own limitations and possible lack of experience of how an impairment can impact on the child's world. They should also be prepared to deal with proxies, - an adult or child who can speak for the child in question where necessary, - and to provide adequate preparation for proxies in their role so that they feel comfortable in accepting the constructs underlying the consultation.

Preliminaries

Before undertaking the conversation with the child the inspector may need to:

- provide for a preliminary and perhaps a further enhancement of the child's analytical and communication skills,
- build in provision for reinforcing the child's motivation and for showing respect to the child (by, for example,

telling him or her who will have access to the data and by letting him or her know when feedback on the outcomes of the consultation will be made available); showing respect will also include being sensitive to cultural diversity and the communication styles and language difficulties of people from other cultures,

- give some thought
 - to redressing the power balance between adult and child,
 - to building a relationship of trust, and
 - to organising the discreet management of the interview /conversation situation so that the child has some control and can lead the direction of the encounter,
 - to recognising the child's concerns about time,
 - to ensuring that the child feels secure and comfortable,
 - to providing opportunities to be reflective about the process.

There will be a need for training and resources (including time) and support systems to be put in place for the inspectorate if they are to undertake these consultations appropriately and successfully.

Methods

In terms of methods often employed to collect data, the 'interview', - where perhaps direct questions are asked, or a conversation is structured around themes, - is often quoted as being useful but a number of indirect approaches are also advocated.

These include:

- using drawings, pictures, photographs, props of various kinds in eliciting responses, and
- having 'conversations' centring around drawings or pictures or vignettes, life-stories and timelines,
- using participative action techniques, drama, focus groups and play,
- engaging a child in casual conversation while participating in an activity with him or her,
- using pair / peer interviews or group interviews,
- having an advocate / interpreter for the child who has been sensitised to the requirements of the role and who accepts the constructs being used (not the same as a proxy who might act in the absence of the child).

Additional methods appropriate for specific cases are described later in this summary.

Themes and outcomes of consultations with children

A range of reports on consultations on a variety of issues which have been carried out with children with and without disabilities in residential care and in the community in the United Kingdom was reviewed to determine the issues addressed and the lessons learnt which might be relevant for the SSI. Factors identified as contributing to the special vulnerability of children with disabilities were identified as falling into three categories:

- the attitudes and assumptions held by society,
- inadequacies in service provision, and
- factors associated with impairment.

Recognition of these factors should underlie any attempts to develop structures and methods to facilitate consultation. In relation to the actual consultations reviewed the range of topics included the inspection process itself (Morgan, 2005), views about services and service providers (Turner, 2003), the participation of disabled children and young people in decision-making within social services departments and issues around it (Franklin & Sloper, 2004), and respite breaks (Triangle, 2004).

In relation to the **inspection process** the following topics were covered:

Information -

- *Did children know about the inspection before it took place?*
- *Did children know about the standards the inspectors were checking out?*
- *Do children know how to get in touch with an inspector?*

Opinions -

- *What did they think of the questionnaires?*
- *How good are inspectors at talking and listening with children?*
- *Do inspectors take what children say as seriously as what staff or carers say?*
- *Do inspectors end up understanding what it is really like for children living here?*
- *Do inspectors get things changed?*
- *Any last ideas for making inspections better?*

Methods -

- *How were they asked their views in the inspection?*

In investigating views about **services** Turner found that responses centred around the following themes:

- *Provision of information (again)*
- *Access and availability of services and issues around Health, Education, Social Care, and Leisure.*
- *Attitudes and behaviour of staff, and*
- *Participation.*

In relation to the participation of disabled children and young people in decision-making within social services departments and issues around it, the questions were categorised around seven themes:

- 1, *Nature of participation,*
- 2, *Characteristics of the children and young people involved,*
- 3, *Characteristics of the participation activity,*
- 4, *Methods of involvement,*
- 5, *Support for children, young people and staff,*
- 6, *Outcomes,*
- 7, *Lessons learnt.*

The responses are reported under the same headings, and reflections, solutions and practical advice are also offered in this report - for example, that many felt that involving children and young people had aided planning, made provision more appropriate and helped to introduce change. They felt that children's views were not necessarily complex, unrealistic or hard to elicit, and that with the right resources, skills and time most children could be involved - even children with complex communication disorders/severe learning difficulties.

Some practical issues were addressed by Triangle and the issue of information sharing comes up again in their work as do attitudes and practical logistical factors which can provide barriers to communication and make access difficult. Additional recommendations are made in relation to: *Consultation forums, and Friendships.*

Specific methods and materials

Materials and methods have been developed by those who believe that these young people have something to say and are capable of expressing a preference and that it is up to those around them to help and support them in overcoming the barriers from initial contact to the actual visit and recording of information. A factor to bear in mind is that children who have communication impairments often experience very low levels of interaction (verbal and non-verbal) with other children and adults, and that when children and young people are treated as if they cannot communicate they sometimes 'switch off'. Building relationships is part of the process, and being able to interpret behaviours as 'indicators of communicative intent' (Morris, 2002) is important.

These behaviours include:

- alternating eye gaze: where a person looks at you then at something or someone else, then at you again,
- clear waiting for a response,
- active seeking of proximity - a person moves to follow or sit close to someone,
- systematic variation in behaviour - if you fail to respond, the person will repeat, elaborate or change the behaviour,
- persistence and intensity of behaviour: if a person repeats the same behaviour in different situations and with different people and seems to do so forcefully.

Lessons learnt from experiences in setting-up and carrying out consultations are detailed, and factors which helped the process are identified. A checklist is provided of important points to bear in mind when finding out about the experiences of disabled children and young people.

Morris lists some important things to find out - such as:

- the person's preferred way of communicating,
- how they make choices,
- how they ask for basic needs to be met.

She also reminds us that the communication needs of the person may change over time and place - how recently have they been assessed?; and that the system used by the child or young person needs to be kept up to date and appropriate to his or her needs. She reports what young people have said helps to maximize their communication potential - this includes:

- having friends,
- having opportunities to make choices,
- having people with high expectations of them,
- having people who respond to what they communicate.

Methods found helpful by the Triangle team in eliciting views included:

- 'Feeling faces' - provided to or drawn by the young people,
- communication of feelings by laughing, giggling, smiling, sometimes grimacing and looking cross or upset,
- communication through body language - touching pictures with a hand or a foot,
- shaking or nodding their head to say 'yes' or 'no',
- pointing to what they wanted,
- leading the visitor to things they wanted them to look at,
- looking carefully at pictures and acting out things that happen in their lives.

Toolkits

Information is provided in the full text of the Review about a range of toolkits which have been developed for use with children and young people with disabilities. The toolkit used by the Turner (2003) study included the following items and could be helpful for the SSI:

- a set of coloured laminated faces and symbols based on a version of Makaton and some work by the NSPCC,
- a set of symbols for good/bad or likes/dislikes,
- a set of issues statements for: a) health and b) education,
- access and availability sheet (snakes and ladders),
- information sheet (best ways to get information graph),
- feelings sheet (an alternative to the Makaton symbols),
- 'tell us about your school' worksheet (could be adapted for health and social services),
- 'have your say' questionnaire,
- helping hand,
- 'what message would you give?' sheet,
- general target, speech bubbles, shapes.

And closer to home, a recently completed study by the ISPCC for the National Disability Authority (NDA, 2006) included consultation with children with disabilities in the family home on issues similar in some ways to those being considered by the SSI. The tools used included:

- flash Cards from the UK Foster Care Association's publication *My Book About Me* which were used as a visual prompt for younger children to encourage discussion around the following themes:
 - family home,
 - being cared for,
 - different standards and rules,
 - helping with chores,
 - going to school,
 - jealousy and rivalry,
 - extended family, and
 - giving and receiving support,
- drawing pictures,

- trigger pictures from the UK Foster Care Association's publication *My Book About Me* which facilitated play-based discussion around the following themes:
 - family make-up,
 - family home,
 - positive family memories,
 - desire for change.
- feeling photos: five photographs showing a young child expressing feelings of:
 - happy,
 - sad,
 - worried,
 - angry,
 - confused.

In relation to children who have severely impaired communication abilities, such as those involved in the studies by Preece (2002) as summarized in the full text of the Review, it has been suggested that for practical and ethical reasons they are most appropriately included in research/inspections by 'being with them'. The range of data collection techniques utilised by Preece included:

- pre-consultation, semi-structured interviews with parents and teachers,
- field notes of the researcher's observations of the children in classroom and care settings before the consultation process began,
- records of structured 'interviews' of children by teachers,
- field notes of the teacher's observations made in the residential setting,

- post-consultation semi-structured interviews with teachers,
- post-consultation semi-structured interviews with residential staff,
- reading documentary evidence: daily notes and children's files.

Further helpful pointers from this study include the following:

- the children were calmer and more secure with known adults,
- their interactions were limited, both with peers and adults, and this affected both their experience of short-term care and the consultation process,
- their use of speech was limited and idiosyncratic,
- they found open questions and choice difficult,
- visually mediated methods strengthened communication,
- their social anxiety shortened the consultation sessions.

Factors which helped to optimize the children's input and the accuracy of the data were also identified.

These included:

- visual support,
- time scales,
- prior knowledge of the children,
- need for triangulation,
- need to address their personal experiences,
- need to be cognisant of each child's individual cognitive, social and communicative abilities.

Conclusion

In this Executive Summary we have addressed some basic general issues for consideration in setting up consultations with children and young people with disabilities. We suggested some ideas for enhancing confidence and assisting the eliciting of information in general and some ideas to assist in cases where communicative abilities were severely impaired. These are intended to provide a starting point for thinking about the procedures and processes which will be involved when the SSI embarks on this new dimension of its activities.

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