CONSULTING WITH CHILDREN WITH DISABILITIES AS SERVICE USERS:

PRACTICAL AND METHODOLOGICAL CONSIDERATIONS

SOCIAL SERVICES INSPECTORATE

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Contents

Overview

This project was undertaken in response to a request from the Social Services Inspectorate (SSI) to undertake a review which would assist the Social Services Inspectorate to prepare for the inspection of children's residential centres for children with a disability in Ireland.

In **Part I**, the introduction to the review, we outline the rationale for consulting children and the framework within which inspections are currently carried out with reference to supporting documentation.

In **Part II** we present a discussion of the issues around the validity, reliability and viability of consultation/research with children with disabilities. The importance of the 'world view' of the inspector is explained and of his or her attitude to children and childhoods and his or her understanding of models of disability. Models of disability are outlined, and the development of a rights-based approach is signaled. The absence of children's voices from research and consultation processes until comparatively recently is noted and reference is made to some of the increasing number of research and consultation projects involving children at various levels of participation. The development and publication of guidelines and methodologies for those consulting with children, with or without disabilities, is reported. Issues arising from these methodologies and the published research findings such as questions of authenticity, reliability and validity, compliance and suggestibility are discussed. Basic considerations in relation to the competence of the child with disabilities are presented, in light of the finding that the process of supporting participation by children in consultation or research is described by most writers as 'challenging'. Additional methodological issues, which have been addressed, are also detailed. It is concluded that the viability, validity and reliability of recent research with children with disabilities may be seen as hinging on the conditions and supports provided for the children and young people who are being asked for their views. These will largely depend on the training and personal qualities of the person doing the consultation.

In **Part III** we present findings from a range of reports on consultations carried out in the United Kingdom with children, with and without disabilities, in residential care and in the community on a variety of issues. The focus is on the issues addressed and the lessons learnt which might be relevant for the SSI. The special vulnerability of children with disabilities to abuse is highlighted, and factors identified as contributing to this special vulnerability are seen 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.

A report on children's views of the inspection system in the UK (Morgan, 2005) yielded insights in the following areas:

- *Did children know about the inspection before it took place?*
- *Did children know about the standards the inspectors were checking out?*
- *What did they think of the questionnaires?*
- *How were they asked their views in the inspection?*
- *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?*
- *Preparing for inspections,*
- *Do children know how to get in touch with an inspector?*
- *Do inspectors get things changed?*
- *Any last ideas for making inspections better?*

A report by Turner (2003), commissioned by the Welsh Assembly, on what children and young people in Wales think about the services they use, found that the overriding messages were related to the following aspects of their lives: *Attitudes and behaviour of staff, Provision of information, Access and availability of services,* and *Participation*. Key findings are also reported in relation to: *Health, Education, Social Care,* and *Leisure.*

Franklin and Sloper (2004) carried out a survey of current and recent activities in social services in England, in relation to the participation of disabled children and young people in decision-making within social services departments. The questions were categorised around seven themes:

- *Nature of participation,*
- *Characteristics of the children and young people involved,*
- *Characteristics of the participation activity,*
- *Methods of involvement,*
- *Support for children, young people and staff,*
- *Outcomes,*
- *Lessons learnt.*

The responses are reported under the same headings. 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 achieve, and that with the right resources, skills and time most children could be involved - even children with complex communication disorders/severe learning difficulties.

Two short reports by Triangle in consultation with United Kingdom social services are also summarized. They are useful in terms of some of the innovative methods they developed of accessing participants, setting up visits, and obtaining the views of the young people. Their findings relate to what makes these young people happy, and how they would redesign short breaks. A set of recommendations focus on the following:

- *Barriers to communication,*
- *Prejudice and discrimination,*
- *Routine and information-sharing,*
- *Contact difficulties,*
- *Consultation forums,*
- *Friendships.*

In **Part IV** we give details of a selection of materials and methods developed to assist the whole process of communication with children with disabilities from initial contact, to actual visit and recording of information. The responsibilities of those around them to respect and promote the rights of the child to communication are stressed, and methods of doing this are suggested. To assist those communicating with young people with limited communicative ability we list 'indicators of communicative intent' (Morris, 2002). 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. Assistive and augmentative communication methods are listed. Toolkits with a variety of methods are described, and helpful pointers are provided on the following issues:

- Setting up groups,
- Expressing opinions for the first time,
- Attitudinal barriers,
- The involvement of others,
- Talking to 'strangers',
- The environment,
- The challenges in trying to consult with a wide range of ages and abilities.

In **Part V** we summarise elements from a number of highly focused small-scale studies in which the methods used are considered to be relevant to this review. All involved the participation of children with disabilities in consultations; some of the children had severely impaired communicative abilities. The questions addressed, the methods used, the findings and the lessons learnt are reported.

In **Part VI** we report briefly the initial reflections of the SSI on the first draft of this review - mainly issues on which their thinking had been sparked off by some of the points made in the literature. It is hoped that further reflection will feed into the next phase of this project - the identification of priorities for the content of a training package.

Part I.
Introduction

This project was undertaken in response to a request from the Social Services Inspectorate in the Republic of Ireland (SSI) to undertake a review which would assist them to prepare for the inspection of children's residential centres for children with a disability.

The SSI has been inspecting children's residential centres in Ireland since 2000 with particular attention to how children in residential centres experience their care, following the landmark study of Clarke (1998), which investigated issues for policy and practice in Irish Children's Homes. The methods used by inspectors include direct observation, review of policies and records, interviews with parents and professionals, and in particular, interviews and less formal meetings (sharing mealtimes and activities) with children and young people.

Inspections are conducted against the National Standards for Children's Residential Centres (not yet adapted for residential centres for children with disabilities), which was published by the Department of Health and Children in 2001.

The main purpose of the review is to assist inspectors to develop methods of accessing children's experiences and to help them become aware that there may be specific challenges in working with children with different types of disabilities.

As a preliminary to the review, the author contacted a number of agencies to establish whether they had ever conducted consultations with children with disabilities in Ireland - the Ombudsman for Children (OCO), Barnardos, St. Michael's House, the National Children's Office (NCO), the Irish Society for the Prevention of Cruelty to Children (ISPCC). While a number of the agencies were currently thinking about consulting with this group, only the ISPCC had actually had some experience of it and was in the process of developing some methodologies. The report of their project was published by the National Disability Authority (NDA) in early 2006 and is referred to in Part V of this review.

The aims of the review

It was requested that the review address in particular the following specific points:
*   Review of 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;
*   Review of 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; despite extensive searching and enquiries we were unable to locate published or recorded evidence of such activities in Ireland;
*   Summary of materials (tools, tapes, videos etc.) developed with a proven record in the area; this was achieved;
*   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 National Children's Office published the National Children's Strategy with a ten-year plan in 2000. The present review may be seen as contributing to all three goals of this Strategy which are as follows:

Goal No. 1   *Children will have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity*

The implications of this goal are spelt out as:
- Encouraging children to express their views and demonstrating a willingness to take those views seriously,
- Setting out clearly for the child the scope of such participation by them to avoid misunderstanding,
- Providing children with sufficient information and support to enable them to express informed views,
- Explaining the decisions taken, especially when the views of the child cannot be fully taken into account.

Goal No. 2   *Children's lives will be better understood - including both individual and shared needs - and their lives will benefit from evaluation, research and information on their needs, rights and the effectiveness of services.*

Goal No. 3   *Children will receive quality supports and services to promote all aspects of their development.*
This will require a reorientation of supports and services so that they provide a strong community-based development, there is renewed emphasis on prevention and early intervention and that supports and services are fully integrated and more easily accessed.

This review focuses on ways of accessing the views and self-perceived status of children with disabilities living in specialist (and non-specialist) residential homes.

The role of the SSI

The enactment in April 2002 of the Children Act 2001, Section 267 amending Section 59 of the Child Care Act 1991 was intended to provide for the registration and inspection by the health boards (now known as the Health Service Executive) of non-statutory residential centres for children with a disability. However, following legal opinion it seems that the amendment would allow only for the registration and inspection of non-statutory residential centres for children with a disability who are in the care of Health Service Executive (formerly the health boards). Further legislation is currently in line for the extension of inspections to all such centres.

The 2003 Annual Report of the SSI states, in relation to the inspection of statutory residential centres for children with a disability, that 'Work is in progress in the Department of Health and Children (DoHC) to allow the legislative requirements to be put in place to allow the SSI to inspect health board (sic.) - provided residential centres for children with a disability and to allow health boards (sic.) to inspect non-statutory residential centres for children with a disability.'

Health Service Executive inspectors currently inspect and register private and voluntary residential centres for children. They do not have a general programme of inspecting services for children with disabilities. However, they undertook a pilot inspection of five private and voluntary services for children with disabilities operating in ten centres during 2004. This was not part of their statutory role, and participation by the centres was voluntary. At present they do not have a regulatory remit over centres catering for children with disabilities.

In the 2003 Annual Report of the SSI there are some references to inspectors' encounters with children with disabilities (p.64) in the centres visited. One centre was commended for the manner in which staff prepared a child with a disability for admission, while children with disabilities in two other centres were noted as being encouraged to participate in all aspects of life and their experiences were not perceived to differ from those of their peers. However, it is not clear whether or not the inspectors actually communicated directly with the children in question.

In the 2004 Annual Report of the SSI it is stated that the DoHC had started work on progressing the legislative changes required to allow the SSI and Health Service Executive registration and inspection units to inspect residential units that care for children with disabilities. In addition, the SSI had commissioned the Health Research Board (HRB) to compile a directory of full-time, respite and holiday residential placements for children with disabilities. Further preparation for the progression of practice in the area is provided by this present review by the Children's Research Centre, Trinity College of literature and practice tools for communicating with and ascertaining the views of children with disabilities. The NDA has carried out a round of inspections of centres for children with disabilities but without any regulatory remit, in order to pilot draft standards.

The inspection process

The inspection process is conducted according to the *National Standards for Children's Residential Centres* 2001 (DoHC), which were produced following:
- The Child Care Act 1991,
- The Child Care Regulations 1995,
- Child Care (Standards in Children's Residential Centres) Regulations 1996, and
- Guide to Good Practice in Children's Residential Centres.

A children's version of the national standards was published in 2004.

Other documents basic to the inspection process include:
- Social Services Inspectorate Practice Guidelines on Safeguarding and Child Protection in Children's Residential Centres (rev. Dec 2003), and
- National Standards for Special Care Units (detention units where children and young people are placed on foot of an order from the High Court).

As yet no national standards have been developed which are specific to residential care units for children with disabilities. It may safely be assumed however that the National Standards for Children's Residential Centres and the National Standards for Special Care Units would be intrinsic to the development of further standards for this group.

The SSI has produced a series of information leaflets designed to inform all those involved about what is entailed in an inspection. These are available on its website: www.issi.ie/inspection.

Inspection of Children's Residential Centres outlines the process by which the SSI conducts inspections into residential childcare services managed by the health boards under statutory powers contained in Section 69 of the Child Care Act 1991. SSI inspectors are authorised to enter any premises maintained by a health board under the act and examine the state and management of the premises and the treatment of children there and examine such records and interview such members of staff as they see fit. The aims of the inspection and the inspection process - for both announced inspections and unannounced inspections - are outlined.

Information for Young People defines what is meant by an inspection, describes the inspectors and the organization for whom they work, reassures the young people that the focus of the inspection is not on them, but on how well they are being looked after, and outlines the rationale for having inspections. The leaflet invites young people to meet with the inspectors and assures them of confidentiality and of feed-back in relation to recommendations, and it lets them know that reports are available on the website and that a short version will be sent to them.

Information for Parents describes the role of the inspectorate, and its position vis-à-vis the Health Service Executive. It describes how the inspections take place (over three days), and details the people consulted - staff and young people, social workers and managers - the documentation that is examined - case files and other records - and the observations that are made of activities. Parents are invited to complete questionnaires and to meet with the inspectors at a time convenient to them during the inspection. It outlines what happens to the information provided by parents and lets them know how to access reports.

Part II.
Review of 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

Underlying issues

Constructions of childhood

Underlying any research (or inspection) project is the 'world-view' of the researcher/inspector. This will determine the kinds of questions asked, of whom they are asked, how they are asked and what happens to the information. Until recent times - perhaps ten years ago - the common 'world view' in relation to children and even more to children with disabilities was that their experiences and views were not useful or valuable or reliable and that it was best if matters relating to children were pronounced upon by adults and that these adults would be able to adequately represent the children. In cases where children were included as research subjects (as was the usual term) parental, guardian or teacher consent was considered sufficient and the child was not necessarily asked to formally give consent at all.

With the widespread ratification of the UN 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.

In Ireland these include a report on key issues for consideration in consulting children and young people, including those experiencing poverty or other forms of social exclusion, in relation to public policy in Ireland. (McAuley and Brattman, 2002). This publication was based on a review of the literature and on actual consultations with children and young people. The issues highlighted range from the debate about consultation itself - reasons why or why not children should be consulted, barriers to consultation, to ethical considerations around consent, confidentiality, equality and inclusion and respect and integrity. It also covers planning and implementation issues and feedback and evaluation.

Models of disability

As well as one's view of children and their rights, an additional element of the researcher/inspector's world-view where children with disabilities are concerned is his/her view of disability. This view will influence interactions with people with disabilities and will be a factor in determining also the questions that are asked, of whom they are asked, how they are asked, and what happens to the information.

Some people with disabilities regard their so-called disability as a positive trait rather than as an impairing factor and see their task as adapting to a life that they can reasonably and purposefully lead. The deaf community provides an example of this attitude and this is one possible model of disability. Over the years, however, services offering support to people with disabilities have developed a number of different models to guide them in their work and these are outlined below.

Individual and medical models of disability focus on the health status of the individual and see outcomes in terms of life situation and social experiences as flowing from the individual's health condition, whether that is a physical, sensory, intellectual or mental health condition or a combination of some or all of these (Good, 2003). These models are based, in part, on the assumption that there exists a norm of a non-disabled person against which disabled people can be measured. This may result in people with disabilities being represented as deviant, unnatural, passive, incompetent and impaired - as what they lack rather than as who they are. These

models may be seen as disempowering, and as reinforcing rather than challenging social exclusion. In addition, they cannot explain the variation in the life experience of different people with the same health condition. They have been said to be instrumental in substantiating the power-base of services and service providers (Moore et al., 1998).

The British social model focuses more on society. It claims that disabled people are an oppressed social group; it distinguishes between the impairments that people have and the oppression that they experience and it defines 'disability' as the social oppression not the form of impairment (Shakespeare and Watson, 2001). Disability is seen as a social construct, which is built upon impairment but is not a necessary consequence of impairment. The nature and degree of impairment will impact on the child's competence to a varying extent depending on the context, including the programmes and services in place from which the child has benefited, and the supports currently available to him or her. The key to the definition proposed by this model is a focus on society and its disabling structures, rather than on the person or persons with impairment (Oliver, 1996).

In its extreme form the British social model denies the existence of impairment in the individuals concerned, and it has been criticised for failing to encompass the personal experience of pain and limitation that is often a part of impairment. In addition, it should not be forgotten that some impairments are invisible but may have functional impacts and implications for personal identity and psychological well-being (Shakespeare and Watson, 2001). French (1993) comments, 'Some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation'; and we are reminded that intellectual impairment, for example, exists in an absolute sense and that people with severe intellectual impairments will always need the assistance of the non-impaired, no matter what adjustments are made to the material circumstances in which they live.

As Good (2003) has pointed out, some critics have argued that the social model is insufficiently attentive to the differences between people with disabilities that exist alongside their commonalities. These critics argue for a theorisation of the heterogeneity of disabled people as a group characterised by diversity, based, for example, on gender, ethnicity, sexuality, age, etc. Such critics would focus more on the fact that people with disabilities are excluded than on possible oppression. McCarthy (2002) points out that the social model does not always relate to the lived experience of people with disabilities. She also suggests that the original social model's central concern with the deconstruction of power dynamics that create and reinforce the experience of exclusion for disabled people raises some challenging issues for researchers wishing to engage in disability research.

A further development of the social model views disability, like childhood, as socially, culturally and historically variable (Barnes, Mercer and Shakespeare, 1999). It has become known as the International Classification of Disability, Functioning and Health (ICF) and was further developed by the World Health Organisation (WHO) in the 1980s.

It 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 acknowledges that different kinds of impairment (e.g. sensory, mobility, communication, intellectual) have varied implications and that one kind of disability does not necessarily imply the co-existence of another in the same individual. This alternative model also incorporates the promotion of positive representations of disabled people; puts ' choice' in place of 'control' and, in terms of outcomes, is focused on 'social action' and 'collective identity' instead of on 'individual treatment' and 'individual identity' (Corker and Davis, 2002). 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. It proposes that children should grow up in an environment that enables them to understand the mutuality and reciprocity associated with respect for each individual (Lansdown, 1996). The goal of this model was to provide an agreed definition of disability and a classification system that would assist researchers in operationalising that definition (Good, 2003). It aims to combine aspects of both the medical and the social model and it conceptualises disability as 'a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc) and contextual factors' (WHO, 2001:8; DPI, 2003). This interaction is seen as being an experience common to all humans across their life span, the conceptualisation thus rejects the notion of the assumed idealised norm that underpins previous understandings of disability (Good, 2003).

The model of disability proposed by the ICF is complex and dynamic, having four dimensions separated into two parts. The first part is composed of the dimensions of Functioning and Disability and it focuses on the individual-his or her body functions and structures and possibilities for activities and participation. The second part focuses on the context (environmental and personal factors) in which the individual lives. Disability is measured by the variables under the dimensions of Activity and Participation - two people with the same body structures and functions may be more or less disabled, depending on a range of environmental factors (Good, 2003).

The NDA offers a definition of disability in line with this view: Disability is 'the disadvantage or restriction of activity caused by contemporary social and cultural organisations which take little account of people who have impairments and thus exclude them from mainstream social and cultural activities' (NDA, 2002b, p.76). Impairment is defined as 'the lacking of part or all of a limb, or having a defective limb, organism or mechanism of the body' (NDA, 2002b, p.76). We would add that it should include psychological mechanisms such as cognitive functioning, the impairment of which may result in learning difficulties, and this is covered by the definition in the Education for Persons with Special Educational Needs Act (2004). A disability is 'a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental heath or learning disability or any other condition which results in a person learning differently from a person without that condition, and cognate words shall be construed accordingly'. Impairments have been recognised in the literature as having the potential to affect any or all aspects of functioning (physical, cognitive, emotional, psychological) depending on the circumstances and the supports available to combat the particular impairment.

Research and consultation with children 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. The earliest to appear were:
- Alderson and Goodey, 1996; Ireland and Holloway, 1996; Ward, 1997; Monteith, McCrystal and Iwaniec, 1997 - a major survey of children and young people with disabilities in Northern Ireland which sought their views on needs and services.
- The ESRC (UK) funded study of Life as a Disabled Child, which was part of the Research Programme on Children 5-16: Growing into the Twenty-First Century (Watson, Shakespeare, Cunningham-Burley and Barnes, 1998) and has given rise to a number of publications.
- More recent studies in the UK, eliciting the views of children and young people with disabilities include: Morris, 1998; Stalker, 1998; Rodgers, 1999; Marchant et al., 1999; Kahn, 2001; Matysiak, 2001; Crisp et al., 2002; Preece, 2002; Turner, 2003; Harrison et al., 2004; Simon et al., 2004a; Simon et al., 2004b; Morgan, 2005; Badham, 2004; Aubrey and Dahl, 2006.

- Some studies in Northern Ireland (Horgan, 2003) and in the Republic of Ireland (Shevlin and Rose, 2003; Kelly and Monteith, 2003) in which children and young people's active participation in the research process was supported and their perspectives were sought.

Methodological guidelines

As well as research findings, there have 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. These include: Beresford, 1997; Morris, 1998; Grove, 1999; Kirkbride, 1999; Edge, 2001; Morris, 2002; Clark, McQuail and Moss, 2003; Save the Children, 2003; Lancaster, 2003; Franklin and Sloper, 2004; Brewster, 2004; Lewis and Porter, 2004; Beresford et al., 2004; NSPCC, 2005; Clark, Kjørholt and Moss, 2005. In Ireland, the publication by McAuley and Brattman (2002) referred to above was followed by a resource pack (McAuley and Brattman, 2003) in which a series of leaflets presented key points for children and young people, but not specifically for those working with children and young people with disabilities, and those who wish to consult with them in relation to the rights of children, what consultation means, feedback and evaluation, issues in relation to planning, ethical considerations, and resources and implementation. It also presented some examples and case studies and provided a list of contacts and useful publications.

The NCO publication *Young Voices - how to involve children and young people in your work* (NCO, 2005) builds on both of these publications, though again not dealing specifically with children and young people with disabilities, and provides working examples of participation in action which are presented throughout the report in sections about the value of participation, planning for participation and implementing participation. It also provides useful resources - contacts, a bibliography of publications, a sample parental consent form, and a sample of a child protection statement.

The NDA in Ireland has published guidelines on effective consultation and enablement of participation by adults with disabilities (NDA, 2002a) and has supported the publication of a discussion paper, guidelines and a checklist for researchers carrying out research with children with disabilities (Whyte, 2005).

Issues for consideration

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. The researcher is responsible, as the inspector would be, for ensuring that the conditions are appropriate for eliciting children's views so that they are reliable. Lewis (2002) elucidated three principles underlying research/consultation which aims to elicit the views of children with learning 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 - this demands that the consulter checks that their interpretations of the views expressed are correct.
- Reliability or trustworthiness - this demands that the consulter checks that the responses are typical of what the person believes and this is of particular concern where communication needs to be facilitated and sustained by clarifying and confirming meanings, whether or not an additional method such as Talking Mats is used to support the interview.

Reliability and validity

Concern has been expressed about the reliability of what children say and whether the credibility of the data might be jeopardised by such factors as suggestibility, compliance or unintended distortion. In studies/reviews/reports that give a voice to children and encourage them to express their perceptions and feelings about their experiences, the onus is on the adult conducting the work to provide the conditions and an atmosphere that will support the child in giving a representation of his or her world that is faithful to his or her experiences. The child's world is accepted as being as s/he depicts it; even if it seems not to be consistent with adult perceptions of that world. This should also apply in the case of consultations/inspections. The inspector needs to be reflexive in considering data from children and needs to find ways of admitting and countering his or her own biases and perhaps prejudices in interpreting these kinds of data. Threats to the reliability of the data as delivered by the child could stem from the conditions under which the data were collected, the rapport established with the inspector, the trust engendered, the child's understanding of the situation and its requirements, the ability of the inspector to communicate with the child and other factors. It is also important to consider the extent to which the data reflect the experiences of the population being consulted and the views of that population.

Some researchers have identified tendencies to which children have been socialised - such as suggestibility, compliance and lying or unintended distortion - as possibly jeopardising the credibility of research findings. This could also happen in consultations/inspections. However, studies have shown that the dangers posed by these tendencies depend very much on the circumstances and that the professional researcher/inspector with special training in sensitivity should have no problems standing over the data obtained. Faithful and accurate recording of both verbal and non-verbal responses in the interview situation and reliability checks on transcriptions should be seen as essential safeguards of reliability. While accepting children's accounts of their own experiences as valid, whether they fulfill tests of accuracy or not, inspectors will seek other forms of evidence when trying to verify points of concern, depending on the seriousness of the issue. Nonetheless, when dealing with children's responses or accounts of their experience, issues of reliability and validity remain problematical as they are with adults (Greene and Hill, 2005).

Suggestibility

The research literature indicates that children's spontaneous accounts of events (obtained without using leading questions) usually reflect their perspective at that moment in time. Repeated questioning about the same events, or repetitions of the same questions, lead children to think that they have not given the 'right' answer and so they change their answers. It has been found that around the margins of events they describe, children are susceptible to suggestions by adults, which may lead them to change details; but they are not susceptible to suggestions by peers (Garbarino and Stott, 1990). Much depends on the researcher's ability to elicit information and to listen to and hear what is being said. The inspector should be aware of his/her own beliefs and possible biases and prejudices, which may affect the ability to accept what is being said by the child as representing the child's real lived experience.

Compliance

This is related to self-esteem and self-image. Often, children after about age five to six (and to greater extent children with disabilities) have been socialized to need approval by adults, and this is achieved by doing or saying what adults want them to do or say. So in a situation involving an interview, children will try to discover what they should be saying or doing in order to win approval, rather than expressing their real feelings. The skill of the interviewer is paramount here in winning the child's confidence so that he or she feels safe to express what needs to be said and feels that what is said will be respected.

Lying/ distortion of events

If a child has been discovered to have lied about an event regarding which there exists objective evidence contrary to what the child has said, the inspector should not be so concerned about the actual content of the lie as the motivation behind it, because that may have a bearing on other issues. The main question is (according to the literature) why is the child telling a lie? Is s/he trying to protect someone? Is s/he afraid of someone or something? Lying may develop as a symptom that expresses the struggle to maintain self-esteem. Children may lie out of anxiety about aggressive feelings, to gain an advantage, to avoid disapproval or to appear better than they feel themselves to be (Garbarino and Stott, 1990). These authors remind us that lying should also be set in the context of family and social life, where children are socialized into accepting that lies are part of living, for example, white lies, social lies.

Addressing the issues

The process of supporting participation by children in consultation/research is described by most writers as 'challenging'. Basic considerations in relation to the competence of the child with disabilities include:

- The developmental status and chronological age of the children, the specific impairments of child participants and how these may impinge on communicative competence,
  - The age and capacity of the children must be taken into account in designing specific measures and prioritising the need for direct participation,
- The nature and severity of their impairment - not simply the category of impairment, but how it affects communication; what support is needed to assist communication - for example, is the child nervous or, alternatively energised in the presence of a stranger? Will this impede communication?
- Ongoing physical health - implications for the style, intensity and frequency of the interactions with the inspector and the nature of the communication between participant and inspector,
- An understanding of the nature of the child's thinking about the world, including their understanding of what is going on, and their ability to reflect on experience,
- Some information about the constructs held by the child in relation to the centre itself, the services provided and possibilities of change,
- Knowledge of the kinds of experiences the child has had and an understanding of the convention of compliance and of deferring to authority figures,
- Skills in maximising self-esteem and self-confidence so that the child is empowered to contribute as fully as possible,
- Availability of objective data as well as observations and conversations,
- The need in some cases for a proxy - adult or child who can speak for the child in question with precautions necessary plus preparation and practice time. The proxy should accept the constructs underlying the inspection.

Methodological Issues

Additional methodological issues which have been addressed in these studies include the following:

- The need for preliminary and perhaps further enhancement of the analytical and communication skills of the child who is being asked to have an input into decision-making,
- Attention paid to redressing the power balance, to build a relationship of trust,
- Provision made for reinforcing motivation for the child to participate,
- Discreet management of the interview/conversation situation: - openness, letting the child lead and have control over the direction of the encounter,
- Recognition of the child's concerns about time - consulting the child about timing the interview for a time that suits the child's routine and does not result in him or her missing other important activities; informing the child of the likely length of the interview,

- Ensuring that the environment/context in which the 'conversation/consultation' takes place is familiar and comfortable for child,
- Awareness of biases within the inspector/researcher - not 'hearing' what is being said by the child for example, in cases of abuse where the adult's concept of the world and relationships is being challenged,
- 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,
- Being sensitive to cultural diversity and the communication styles and language difficulties of people from other cultures,
- Showing respect for the child by 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.

Conclusions

The viability, validity and reliability of recent research with children with disabilities may be seen as hinging on the conditions and support provided for the children and young people who are being asked for their views. The issues that are investigated, the methods used to elicit information and the uses to which the information is put will depend on aspects of the world-view of the inspector/researcher - specifically to his/her view of the child and childhood and his/her views on disability and its causes and effects. The process of supporting participation by children in consultation/research is seen as challenging and a number of issues need to be considered before undertaking such consultations. These include considerations in relation to the competence of the child and methodological issues around the process and implementation of the consultation/research. Even when due precautions are taken there may be problems with reliability and validity, just as there are with the testimony of adults and these should be admitted. 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.

Part III.
Review of 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

Consultations with children and young people with disabilities reported in recent publications have taken a rights based approach - that children have a right to be heard and have a right to be supported in achieving their potential to give their views - and have been based on an adaptation of the social model of disability. A number of relevant reports related to services for children with disabilities have been published in the UK in recent years. The reports arise mainly from inspections or consultations involving children with disabilities in relation to residential or other care services. Those involved appear to have been satisfied that the possible points of contention discussed above were adequately considered and that the process was reliable, valid and viable. A search revealed no records of police investigations or other inquiries in Ireland or the UK for which the views of children with disabilities were elicited

The reports summarized in this section include:
NSPCC (National Society for the Prevention of Cruelty to Children) *It doesn't happen to disabled children: report of the national working group on child protection and disability.* London: NSPCC, 2003.

Morgan, R. *The children's view of inspection: first report of children's audits of inspections by the Commission for Social Care Inspection.* Children's Rights, 2005 (www.rights4me.org.uk).

Turner, C. *Are you listening? What disabled children and young people in Wales think about the services they use.* Barnardos, Children First, NCH, 2003.

Franklin, A. and Sloper, P. *Participation of disabled children and young people in decision-making within social services departments: a survey of current and recent activities in social services in England.* University of York, 2004.

Simon, J., Tuckett, P. and Marchant, R. *Good points and bad points: consultation with disabled children and young people in Gloucestershire.* London: Triangle, 2004.

Harrison, G., Tuckett, P. and Simon, J. *Thumbs up, thumbs down: consultation with disabled children and young people in Warwickshire.* London: Triangle, 2004.

Aubrey, C. and Dahl, S. *Children's voices: the views of vulnerable children on their service providers and the relevance of services they receive.* British Journal of Social Work, 36, 21-39, 2006.

While SSI inspectors aim primarily to consult children about the care they are receiving, they will also be on the alert for dimensions of the children's experiences which might emerge coincidentally and should certainly be watched for. These would include abuse of all kinds.

NSPCC Report: *It doesn't happen to disabled children: report of the national working group on child protection and disability.* London: NSPCC, 2003.

This report pointed out that disabled children are particularly vulnerable to abuse. It reminds us of how difficult it can be to accept that disabled children could be victimized physically and become targets of systematic sexual and other abuse. It drew attention to the evidence of such abuse (particularly in residential settings in the UK and the USA) and to the finding that it was almost impossible for disabled children to obtain redress through the criminal courts. The factors that create disabled children's vulnerability are identified as falling into three categories: the attitudes and assumptions held by society, inadequacies in service provision, and factors

associated with impairment. Some detail on these is included here as they provide a good basis from which to start thinking about the possibility that evidence of abuse may be encountered and because indicators of potential abuse should be among those informing the work of inspectors in residential settings.

Attitudes and assumptions include:
- The devaluing and disempowering of disabled people by society and the existence of negative attitudes which make it less likely that disabled children will be listened to about their experiences of abuse, and also that they are more vulnerable to intimidation and bullying,
- Lack of awareness among carers and professionals of what the indicators of abuse are for disabled children,
- Assumptions made about the effects of impairment which can result in indicators of abuse being mistakenly attributed to the child's impairment,
- The belief that disabled children are not abused which can lead to a denial of or failure to report abuse,
- Sometimes a failure to recognise the impact of abuse on disabled children.

Inadequacies in service provision include:
- Barriers to participation in society facing children with disabilities and their families,
- Isolation due to poorly coordinated support services,
- Gaps between child protection workers and care workers,
- Lack of holistic assessments,
- Lack of access to assistance with communication for disabled children - sometimes communication systems lack the necessary words,
- Failure to consult with disabled children about their views, wishes and feelings,
- Dependency on an abusing carer can create difficulties in avoiding or communicating about abuse,
- There is often little effective sex education or safety and awareness work with disabled children,
- Disabled children (or anyone close to them) may be inhibited about complaining because of a fear of losing services,
- Disabled children may not have anyone to turn to, they may lack the privacy to do this and the person to whom they turn may not be receptive to the issues being communicated.

Factors associated with impairment, which could contribute to abuse, include the following:
- Disabled children may receive intimate care (possibly from a number of carers) which may increase the risk of exposure to abusive behaviour,
- Disabled children may have an impaired capacity to resist or avoid abuse,
- Disabled children may have communication difficulties or lack of access to an appropriate vocabulary, and this may make it difficult to tell others what is happening.

It is likely that similar influences operate in Ireland. *Children First: national guidelines for the protection and welfare of children* in the Republic of Ireland, devotes a chapter to additional guidance concerning children who may be especially vulnerable, including children with disabilities and children outside the home. The reasons why they may be vulnerable are listed, and it states that research has shown that abuse of children with disabilities is a significant problem. Parents, teachers and all staff in services for children with disabilities need to be familiar with the indicators of abuse and to be alert for signs of abuse. All agencies working with children with disabilities should have clear guidelines for preventing, identifying and reporting child abuse and should ensure that staff and volunteers are trained in the use of the national guidelines. The procedures to be followed are detailed in the report. Paul and Cawson (2002) provide a summary of the findings from a review of the literature which

revealed the vulnerability of disabled children to abuse when living away from home, the measures that can be taken to protect them, and the limitations of available data as a basis for planning child protection measures.

A bibliography on child protection issues with disabled children is provided under a separate heading in the References section of the present document.

Morgan, R. *The children's view of inspection: first report of children's audits of inspections by the Commission for Social Care Inspection.* Children's Rights, 2005 (www.rights4me.org.uk).

Morgan was not solely concerned with children with disabilities but the findings in his report were thought to be relevant to the present review as they represent almost an 'inspection' of the inspection process carried out with children. The report is based on interviews with 153 children living in children's homes, boarding schools and residential special schools, and in addition on questionnaires sent back by 103 children in boarding schools, children's homes, foster homes, residential special schools and a residential family centre.

While it does not cover the methods used with children with disabilities (and indeed makes very little mention of this category) and it accessed children who were articulate and did not have communication difficulties, it is felt nonetheless, that the kinds of information obtained might be useful for the Irish system.

The questions asked and responses obtained (in summary) were as follows:

1. Did children know about the inspection before it took place?
Most did know and had been told by staff or by means of a poster.
Most children thought they had had enough notice.
They had very different views about what the inspection was for.
Children need to know that they can tell inspectors what things are really like and that they don't have to make their service sound good.

2. Did children know about the standards the inspectors were checking out?
Most knew nothing about the standards and those who were interested wanted them in a children's version. Some felt that they didn't need to know the rules so as to be able to tell the inspector whether their establishment was up to standard.

3. What did they think of the questionnaires?
This was their only way of giving their views to the inspector for many children.
Some would have preferred to speak to an inspector and would have liked to have the option with notice.
A number of suggestions were made for improving the questionnaire. It should be:
- Shorter,
- Easier to read,
- Include more pictures,
- Have responses to choose from,
- Tick a box rather than spaces to write,
- Have questions about what is important for children,
- Anonymous if children wanted that,
- Voluntary - no pressure to complete.
The interview could then follow up on what children think is important.

4. How were they asked their views in the inspection?

Over 25% had not actually spoken with the inspector.

25% had been able to talk with the inspector at meals or while showing the inspector around.

They should be told before the inspector arrives that they can tell him/her things.

If a visit is unannounced, some children may be out - they should be rung later by the inspector to see if they want to say anything.

It is nice to have choices about meeting with the inspector - talk alone, in a group, over a meal.

5. How good are inspectors at talking and listening with children?

Seventy eight per cent said that the inspectors they met were good at listening to children. It was suggested that the initial questionnaire should ask you to say if you would like to speak privately to the inspector. They liked the fact that talking with them was voluntary. Some children found it difficult in a group.

They felt that:

- Children should have an opportunity to ask questions and raise issues - not just inspectors,
- Where not all children are able to speak, inspectors should listen to those who can,
- Inspectors should be good at other sorts of communication - symbols, signing, interpreting eye movements,
- Inspectors should be aware that not all children want to talk to them.

Inspectors did not always interact actively; children did not always see the point of what inspectors were asking, nor of chat not directly related to the point of the inspection. It was felt that it is best when inspectors just listened and also explained who they are and why they are there. Inspectors should not give personal views to children nor ask children personal questions not related to whether or not the establishment is being properly run. Some inspectors were better at working with groups; others at talking with individuals; some were better in pairs, some were better alone; some were better at avoiding misinterpreting what children said.

Children want to know what inspectors think of their home or school. If they raise issues they should be taken into account.

There were mixed views on whether or not staff should be around.

6. Do inspectors take what children say as seriously as what staff or carers say?

It was recognised that staff are usually keener to talk and easier for inspectors to talk to than children are, and it was thought that inspectors tend to believe staff more than children. It was thought best if inspectors ask children's views first and then asked children to show them around before speaking with staff, and that they should spend more time with people and less with paperwork.

7. Do inspectors end up understanding what it is really like for children living here?

In order to develop this understanding the children recommended that inspectors should spend time with children getting to know what life is like {here}, join in activities, including those outside the establishment, stay overnight, at weekends, and speak to the children away from the setting.

8. Preparing for inspections

It was said that most homes and schools get things ready for inspections - things are different from usual at inspections; staff act differently; there is minor camouflage. This points to the need for 'sudden inspections', and the need to ask children how the home or school has been made different for the inspectors to see.

9. Do children know how to get in touch with an inspector?

Twenty-nine per cent knew how to get in touch with an inspector if they wanted to. They were not clear who you would reach by using a Helpline. They felt that it was good to know they could call an inspector if needed and to know if someone higher would be needed in order to accomplish anything.

10. Do inspectors get things changed?

Forty-eight per cent said nothing changed; 16% said change happened. Fourty one per cent of children thought that change was needed. The children thought that inspections should always lead to something changing for the better, if the inspectors thought there needed to be change. There was some concern expressed that inspectors listened but nothing happened...a feeling that inspectors were powerless to make things happen if staff didn't want it to. It seemed particularly difficult to change anything that was to do with staff. On the other hand, having an inspection sometimes caused good things to happen in advance.

11. How well are we doing?

Half of the children thought inspectors were doing well and approved of the fact that they could choose children to speak to at random. However, there were some recommendations:

* Inspectors should be neutral - not coming in with own ideas first,
* They should be less interested in buildings and things than in what it was like for the children,
* Inspectors should ask children before reading private files and should keep conversations confidential - children were afraid that inspectors would tell staff what they had said.

There were mixed views on whether same or different inspectors - it depended.

12. Any last ideas for making inspections better?

* Have male and female inspectors/visitors,
* Visit more often and visit unannounced,
* Children could help design questionnaires,
* Spend more time with children rather than staff,
* Tell children what they are doing and what they are looking for,
* Need to check some things in more detail,
* Inspect, then check with children, then inspect again,
* Children could be asked to make a list of any complaints they had about the inspection,
* Change should be relevant for people there at present, not just in future,
* Give feedback report to children - that covered what staff had been asked to change - this should be a summary - maximum 2 pages - what is good, bad, and what needs to be changed,
* Parents should get a copy of the report and it should be put on the internet,
* Importantly, follow-up checks should take place.

Turner, C. *Are you listening? What disabled children and young people in Wales think about the services they use.* Barnardos, Children First, NCH, 2003.

Turner (2003) reported on a survey of 105 disabled children and young people in Wales aged 5 - 25 who had multiple disabilities and complex needs. This report had a wider remit than simply looking at residential care - it included all services, but it was felt that the findings and methodology would be relevant to the present review. The participants included children and young people with autism, cerebral palsy, Attention Deficit Hyperactivity Disorder (ADHD), Down's syndrome, mobility and access difficulties, sensory disabilities (primarily speech and hearing impairments), mental health difficulties and chronic illness. A variety of 'traditional' and creative

methods were used during the consultation including one-to-one and group interviews, express cards, ranking exercises and draw and write methods. The overriding messages from the consultation were related to the following aspects of their lives:

Attitudes and behaviour of staff - this had the greatest impact on their experiences of accessing services. There was frustration and distress where they were not listened to with understanding and respect.

Provision of information - there were serious gaps in their understanding of their own disability, care and treatment, roles and responsibilities of staff, services they receive and services that are available. This information often came 'second hand' via parents or carers and not directly from professionals. Restricting information about a medical condition may mean that there is a restriction of information given in other areas and may have the effect of limiting consultation as a regular practice. The provision of information about rights was not touched on explicitly in this report, but should be included, as should the acknowledgement and recognition of actions promoting rights.

Access and availability of services - both physical and attitudinal barriers were noted. Transport was a key issue - particularly the time spent travelling to school or hospital. More choices were requested. Support was provided for some, but not to all, who needed it.

Participation - involvement in making decisions about their own care and treatment was not consistent across services. Small decisions were made by disabled children and young people but adults still appeared to make the more important decisions on their behalf and there were few examples of their involvement in shaping services. They wanted to participate in decisions about their own individual care and the services they use. Even if the range of choices was limited, they should know about them.

Key findings are also reported in relation to: Health, Education, Social Care and Leisure, and these are summarized below as they might have relevance for the SSI.

Health
Many disabled children and young people were anxious about attending hospitals. They disliked the smells in hospitals and the quality and choice of food. They said that hospitals which were colourfully decorated were nicer places to visit and that there should be more fun things to do in hospital. They wanted to be taken seriously and listened to by medical staff but information provided by doctors was not always presented in a way that the young people could understand. They felt that transition services did not meet the needs of many disabled young people but that medical staff's small gestures and a positive attitude could make all the difference. They expressed three top priorities:
• To be able to have someone with you (when you stay in hospital),
• Not too much waiting,
• Doctors and nurses you can talk to.

Education

Disabled children and young people had very mixed views and experiences of school and college. They valued formal and informal support from their peers and would like to be more involved in providing support to others. Making friends is very important, but bullying is a significant issue in both mainstream and special schools. Many of them felt that many teachers did not listen or understand their needs but that teaching support staff were very helpful. Many of the children had long journeys to school and school dinners were not popular. Transitions were difficult times for them and they needed more options and support. The top three priorities were:

- Mixing with children and making friends,
- Good healthcare in school,
- Non-judgmental environment.

Social care

Adaptations and equipment featured heavily in the lives of some of the children and young people. They appreciated extra support but this was not available to all. They were largely positive about short break and family link carers but they had mixed views about spending time away from home with short break services. They enjoyed taking part in activities outside the home with the support of family help or outreach workers, though some preferred one-to-one support rather than group activities. They felt they needed to be given clearer information about the roles and responsibilities of social care staff. Their priorities were:

- Routine and reliability,
- Choice and control,
- Opportunities to make decisions.

Leisure

They needed the option of spending time away from their parents. The majority of disabled children and young people felt most comfortable attending leisure services exclusively for disabled children and young people, and many of them needed support from parents or siblings in order to attend inclusive leisure services. They were generally enthusiastic about the leisure services they accessed but they would like more choice, and some older disabled young people felt that they were 'missing out' on a good social life. Priorities were:

- Freedom, choice of activities,
- Transport,
- Staff who are supportive but not over protective.

Franklin, A and Sloper, P. *Participation of disabled children and young people in decision-making within social services departments: a survey of current and recent activities in social services in England.* **Interim report: University of York, 2004.**

This report was funded by the UK Department of Health's Quality Protects research initiative. The Quality Protects programme was launched in 1998 with the aim of transforming the management and delivery of services for children for whom social services have direct responsibilities: children who are looked after by local authorities, children in the child protection system, and other children in need requiring support or help from social services.

Objective 8 of the Quality Protects programme was: 'To actively involve users and carers in planning services and in tailoring individual packages of care and to ensure effective mechanisms are in place to handle complaints.' Its sub-objectives were:

- To demonstrate that the views of children and families are actively sought and used in planning, delivery and review of services, and
- To demonstrate that the satisfaction of users with services provided is increasing.

The objectives of the research were:

- To identify participation work which involved disabled children and young people,
- To establish factors which could support and promote good practice in the process of assisting disabled children and young people's effective participation,
- To establish factors which can support and promote good practice in outcomes of disabled children's and young people's participation, in respect of the impact of their views on service development and/or tailoring individual packages of care.

A two-stage approach was undertaken to the survey. A screening letter and information sheet were sent to all Assistant Directors of Children and Families teams within social services departments in England (N = 150) asking them to:

i)   Indicate if their department had undertaken any work in the last 12 months on involving disabled children and young people in decisions regarding their own care or in the design, delivery or evaluation of service,
ii) Indicate if they would be prepared to complete a questionnaire about this work,
iii) Supply a contact name and address of someone who could complete the questionnaire and provide further details.

The response rate revealed that 79% of social services departments reported that participation work was being undertaken and 79% indicated a willingness to complete the detailed questionnaire. Seventy per cent of them actually responded. The findings are considered to be a snapshot of current activity, although the research is not exhaustive and there were limitations to the data collected.

The questions were categorised around seven themes:

- **Nature of participation** (whether children and young people were involved in decisions regarding their own care, or whether involvement was in general service development, planning or evaluation),
- **Characteristics of the children and young people involved** (numbers, age range, and whether the children involved had complex health needs, autistic spectrum disorders, communication impairments and degenerative conditions),
- **Characteristics of the participation activity** (description and aim, funding, partner agencies),
- **Methods of involvement** (written, verbal, visual and computer; whether children were involved individually or as a group),
- **Support for children, young people and staff** (type of support and any specific support tailored for disabled children),
- **Outcomes** (changes in service provision, commissioning, or in service priorities; feedback given to children and young people),
- **Lessons learnt** (staff views on their experience of what was useful or problematic).

At the end of the questionnaire, respondents were asked if there was a post-holder in the organization with designated responsibility for children and young people's involvement. The results are presented here in summary under the headings given above.

1. Nature of children's participation

60% reported involving or having involved disabled children both in service development and within decision-making regarding their own care, and 40% in one or other of these categories. The numbers involved ranged from less than ten to over 50. The findings suggested that the initiatives generally did not entail large-scale consultations with children about service development or decisions regarding their own care. The age range of children involved in the initiatives went from 5 to 18+, and it was found that 90% of respondents were involving disabled young people from the age of 11 years, and three in ten were involving children of five years old with decisions about their care. There was a similar pattern for general service development.

2. Characteristics of the children and young people

In terms of decisions about their own care, 71% of the initiatives involved children and young people with degenerative conditions, 97% with communication impairments, 88% with autistic spectrum disorders, and 77% complex health needs. With initiatives in the area of service development, the corresponding figures were that 53% of the initiatives involved children, although this figure did not concur with information from other sources and it was thought that the actual numbers of these 'difficult to reach' children who participated were small. The survey does not give insights into the methods being used to involve these groups of children or the equitability of their involvement. However, these questions are the focus of stage three of the project.

3. Characteristics of the participation activity

a) *Individual care packages:* Disabled children and young people were more likely to be involved in their reviews than in any other decision-making process with 80% of respondents stating that they involved disabled children and young people. Over six in ten respondents reported involving children and young people in decisions about their respite and care planning, and over half involved children in transition planning and assessments. Around a third involved them in decisions about leaving care and residential care accommodation; and the least likely areas of involvement were child protection conferences and health plans. Examples of documentation which they had developed to support young people's involvement were provided by three authorities. Only one of them appeared to have been directly designed for use with disabled children and young people.

b) *Service development initiatives:* Eleven per cent of the 70 initiatives were youth forums which were involved in a wide variety of activities including training and interviewing social services staff, consulting with other young people, producing newsletters and general consultation work around service developments such as transition. Involvement with play/leisure/recreation activities was at about the same level. These appeared to be one-off involvements asking disabled children for their opinions of activities, equipment, toys, décor, and changes to buildings or gardens, within respite care, resource centres and short break centres. Other initiatives where disabled young people and children were involved included: recruitment (four authorities - of whom three had provided training for staff in communicating with young people), information provision, and involvement in 'Best Value' reviews. Other initiatives included short breaks, producing a newsletter, direct payments and 'other'.

c) *Funding:* Dedicated funding had been provided in 54% of the authorities to support disabled children's involvement in tailoring individual packages of care, and in 64% of initiatives within the area of service development.

d) *Partner agencies:* Over 80% involved partner agencies - with the voluntary sector featuring highly in just under half of all projects. Some initiatives involved a wide range of partners.

4. Methods of involving disabled children and young people in decision-making
The majority of service development initiatives involved children both individually and in a group, and both methods have merits and disadvantages. Nearly 25% were single once-off exercises with just over a quarter being arrangements lasting over one year and nearly a further 25% being permanent arrangements suggesting possibly a more sustained approach to disabled children and young people's participation.

Details were requested on methods of involving the participants, but responses were patchy and should be treated with care. It was found that 52% of those involving disabled children in decisions about their own care were using a written method - in most cases a questionnaire or consultation form. Within the area of service development, 54% of the initiatives were using written methods, predominantly questionnaires, although some employed newsletters, graffiti walls, or distributed minutes from meetings - usually at youth forums. A verbal method of involvement appeared to be more widespread, being used in 88% of initiatives for decisions regarding own care and in 87% of those targeting service development. Interviews were widely used in both decision-making areas. Discussion groups, meetings and workshops appeared popular for service development along with the availability of advocates for individual decision-making. Eighty-five per cent were using visual methods to facilitate involvement - Symbols, Makaton, Picture Exchange Communication System (PECs), or signing or toolkits such as '*I'll go first*', and this was the case also for 66% of the service development initiatives. Art and drawing featured highly across both decision-making areas, and creative methods such as photographic diaries and videos were being employed. Observation work was also mentioned in a few cases possibly indicating some move towards including children with severe difficulties and/or communication difficulties. Using a computer or I.T. methods of involvement was less common - it happened in 40% of initiatives involving decisions about own care and 33% of those related to service development.

Overall, a wide variety of methods were being adopted to involve disabled children and young people with decision-making. In addition to those already mentioned, artistic methods such as role-play, drama and puppets were also being used in a few cases and many authorities were combining methods.

5. Support for children and young people taking part
 Support is needed so that children and young people can understand the process and become empowered to participate effectively in what is more often than not an 'adult' environment. 83% of the respondents involving children and young people in decisions regarding their own care stated that they provide support in order to facilitate their involvement, although this support was described as 'minimal' in a couple of authorities and variable according to the commitment and/or availability of social workers to facilitate it. Support varied across all areas and even across teams within a single authority. Fewer authorities (76%) provided support in initiatives involving children and young people in service development and again, it was variable.

The forms of support most frequently offered were assistance with communication, transport and access to venues for both kinds of decision-making. But there were still low levels of training for children and young people and little information about the authority's decision-making process, both factors which may help a child's understanding of the process and encourage fuller participation and empowerment. Within decision-making for individual care, none of the nine initiatives offering training were making similar provision. The training being provided included computer training, group work skills and raising confidence, travel training, and specific training on communication techniques such as Makaton, British Sign Language and using the '*I'll go first*' package. Nine initiatives were providing service-development decision-making. This was mostly centred on providing young people with skills to work together in a forum. Computer-aided assistance involved the use of 'Widget', 'Viewpoint' and 'Symbols' for both kinds of decision-making.

6. Training for staff

For the vast majority of respondents training for staff had centred on communication and communication methods. Two voluntary organizations (Triangle and The Children's Society) were noted as having provided considerable support with regard to training specifically for the involvement of disabled children and young people. A number of staff members, however, stated that they felt their training had been minimal and limited. Training appeared to be similar for those workers involved in the two different areas of decision making although the processes and skills required to involve disabled children in these two different decision-making areas would be quite different. The data also indicated that there were relatively low levels of 'protected time' offered to workers undertaking participation work - it was available to only 22% of those involved in children's decisions about their own care and to 37% of those involved in children's decisions about service provision.

7. Feedback given to children and young people

Feedback is valued by children and young people for a number of reasons including;
- Finding out the views of others,
- Knowing what it is planned to change and when, and
- Understanding the reasons when their ideas are not implemented.

Within decisions about individual care packages, 17% of areas indicated that they did not provide any feedback and a total of 80% stated that they did, although seven of these did not give details on how they did so. For the remaining 45, feedback was mainly verbal through a social worker, key worker, or advocate, or provided during the review process. When written information was provided it was invariably to parents. A number of respondents suggested that feedback was not always given in an appropriate format, using a communication method suited to the needs of the young person. With involvement in service development, feedback to disabled young people was also patchy, with a number of respondents indicating that feedback was given to their parents. Again verbal feedback appeared to be the most popular and written minutes from a forum. A few initiatives provided examples of reports being shared with young people, although it was not always clear if they had been made accessible to the young people.

8. Outcomes

Respondents were asked to indicate whether the service development initiatives had led to developments in services and if so what kinds of changes had resulted. Only 44% indicated that there had been changes to service provision but these had been mostly through altering activities and/or changes to décor. Another reported outcome was better information provision including information on transition and a CD-Rom on being looked after. Other outcomes reported by individual authorities included an advocacy service, new equipment, a use-friendly register, inclusion in reviews, communication packages, transition planning, the development of a disabled children's participatory strategy, and changes to Direct Payments.

A couple of respondents suggested that the involvement of disabled children and young people had led to a change in culture with a raised awareness that they should be more involved. The authors of the report pointed to the need for systematic evaluation to ensure that participation activity is successful, appropriate and without negative consequences.

9. Reflections

The survey also sought reflections from respondents on any experiences they felt might be particularly useful to others and asked them to identify issues that were problematic. Responses were similar for both decision-making areas.

Most of the difficulties concerned *lack of time and resources*. Recognition was sought that the involvement of disabled children can be very time consuming if it is to be meaningful. Lack of time was seen as a significant problem which impacted on the quality of children's involvement.

Respondents said that this meant that they did not have adequate time for their own preparation, or for listening to or preparing children, for example for attendance at their own review. Lack of time limited staff from finding or developing appropriate methods and resources, for example adapting consultation forms, or from being able to spend enough time with a child in order to understand their communication method.

Equally problematic was a reported *need for training, skill development and experience* in understanding this kind of work. This included the need to be skilled in neutrality and objectivity - not being tempted to put words into the young people's mouths, or to be skilled in interpreting and representing children's views, particularly children who do not use speech to communicate.

Difficulties were encountered with *gatekeepers*. Some had to be persuaded of the need to involve children in decision making, and respondents wrote of being prevented from accessing the views of young people or of staff assuming that children would not be cooperative. Of concern also was the difficulty in reconciling differing views and opinions gained from children and young people and from their parents and the need to handle this sensitively.

There were also difficulties involving *particular groups of young people*. Those with communication difficulties, autism or severe epilepsy were mentioned. It was suggested by the data that there is a *shortage of advocates* skilled in using alternative methods of communication to access the views of these groups.

Some respondents raised the issue that many disabled children and young people lack confidence and experience in giving their views.

10. Solutions and practical advice
A number of useful points of advice were given:
- Be clear about your aims and objectives,
- Be realistic and do not expect too much at first,
- Consider practical arrangements such as wheelchair accessibility, transport,
- Undertake involvement as early as possible,
- Tailor methods to each individual child,
- Do not treat disabled children as a homogenous group,
- Be creative,
- Use available resources - pictures, symbols, photos, 'I'll go first',
- Allow sufficient time to prepare and have protected time in order to undertake the work satisfactorily,
- Allow time for the young people to build up their own confidence and skills,
- Build up relationships with young people in longer-term service development initiatives,
- Spend sufficient time with the child/young person in order to get to know them and understand their communication method,
- Consider that children with complex communication methods might be best supported in their communication by someone who knows them well or that this person could offer advice,
- Have sufficient funding and resources available,
- Access training,

- Keep information simple and jargon free,
- Make sure all staff feel included,
- Do not make assumptions,
- Be honest,
- Have a positive approach,
- Do not be afraid!

11. *Positive reflections*

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 achieve and that with the right resources, skills and time most children could be involved - even children with complex communication disorders/severe learning difficulties.

Simon, J, Tuckett, P. and Marchant, R. *Good points and bad points: consultation with disabled children and young people in Gloucestershire.* London: Triangle, 2004.

This consultation was carried out by Triangle, an independent organization providing training consultancy and direct services for young people on behalf of the Social Services and Education Department of Gloucestershire National Children's Homes (NCH) County Council alongside the three Primary Care Trusts in the area and NCH. It was intended that this consultation would begin a local process of working in partnership with disabled children and young people about how services are developed. Triangle was to work with local agencies for 18 months providing training for practitioners after the consultation, ongoing consultancy, and a conference.

The 38 children and young people were aged from 9 to 18 and had severe learning difficulties, profound and multiple learning difficulties and physical impairment. None had solely a physical impairment. Four hundred parents and carers were written to and told about the consultation and asked for their consent for contact details to be sent on. Eighty-seven gave their consent and 40 were randomly chosen (two families were not at home when they called).

Their approach included a leaflet written specifically for the young people enclosed with the initial letter to the families and a second letter to the young person once the visit had been arranged, together with a photograph of the visitor who was to talk with them. To ensure anonymity, children were visited in their own homes rather than in the service. A number of approaches were used to enable young people to express their views - 'feeling faces' was one example, drawing was another.
(Many of the findings in the Turner paper are common to this report.)

It was found that young people want:
- To enjoy their lives,
- To have their needs recognised and met,
- To be safe at school and not be bullied,
- To have friends,
- To have more freedom to choose what they do and when they do it,
- To be listened to and have their views taken into account.

Recommendations included the:
- Need for services to be child-centred, respecting children as individuals and treating them accordingly,
- Need to feel that staff who are there to support them can be approached and are not too busy to be disturbed,
- Need to be enabled to make choices in all aspects of their lives,
- Need to have information about medical and other appointments and to know who has information about them and whether their consent is needed to pass information between agencies,
- Need to know how to make a complaint about something they feel is not right,
- Need to have issues of physical access addressed,
- Need to have anti-bullying policies in schools reviewed,
- Need to have ways developed of developing and facilitating friendships,
- Need to have advocates who will support them in challenging discrimination and instituting anti-discriminating practice,
- Need to be facilitated to build links with disabled adults.

Harrison, G, Tuckett, P and Simon, J. *Thumbs up, thumbs down: consultation with disabled children and young people in Warwickshire.* London: Triangle,2004.

This consultation, also carried out by Triangle, focused on short break services and how to facilitate children and young people's involvement in the redesign of short break services. Twenty children aged 5 - 16 and five Triangle visitors were involved. The consultation group included children with severe learning difficulties, children with cerebral palsy, children on the autistic spectrum, children with profound and multiple learning difficulties, and children with a physical impairment. In addition, the visitors met with a further eight young people who attended the Wacky Forum - made up of two representatives from each of the special schools in Warwickshire. The questions asked were narrowed down to the following:
- How does it feel for you now to use a particular service?
- What is good about a particular service?
- What is bad about a particular service?
- What could be better?

Triangle were prepared to translate leaflets and to use interpreters if necessary. Similar procedures were followed as for the Gloucestershire exercise. Photographs were used extensively - generic photographs of doctors, nurses etc., activity photographs, photographs of the school entrance and of some members of staff. Interviews took place in the children's own homes, sometimes with the young person alone, and sometimes with one or both parents and/or sisters and brothers who were able to provide detailed knowledge of the young person's communication methods particularly for those who relied on non-verbal communication.

The approaches used 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.

Some young people talked a lot, others used just one word at a time. One child had a switch to help her communicate. Widget symbols and beanbags with different faces on also aided communication.
Some children were able to communicate through drawing pictures.

The recommendations centred around seven main issues:

i) *Barriers to participation* - The children and young people enjoyed a wide range of activities, but barriers to participation were encountered and these need to be addressed by service providers - such as a child waiting so long for equipment that it did not fit him when it arrived.

ii) *Communication* - In many cases it would not have been possible to communicate with the young person without a parent or a sibling present because the visitors did not have enough information about how the young people communicated and the young people themselves were often unable to explain. A 'communication passport' is suggested to explain how people communicate so that people who do not know them very well can learn quickly. It should be kept up to date. Services should ensure up-to-date assessment of communication needs as well as ongoing advice, guidance and supply of communication aids and equipment.

iii) *Prejudice and discrimination* - There was evidence that some children and young people had already faced prejudice and discrimination. Disability training for all staff was recommended so that there is a shared understanding across all agencies of the pervasiveness of discrimination, the detrimental effect it can have on young people's lives, and the importance of challenging it when it surfaces.

iv) *Routine, and information-sharing* - There was a large group of children who expressed a strong dislike of change or disruption to their routine. Good preparation for change should be available across all services. This could include visual timetabling using photographs and symbols as a way of informing young people about what they will be doing each day. Children need to know who wants to see them, when their appointment is, and why it is happening. They should know who has information about them and whether their consent is needed to pass information between agencies.

v) *Contact difficulties* - Up to date contact details should be held by Health and Social Services.

vi) *Consultation forums* - The Wacky Forum was impressive, but should be opened to more disabled young people.

vii) *Friendships* - The children and young people showed how important friends are to them, and they valued the opportunities they had to meet their peers. This should be facilitated more by services.

Aubrey, C and Dahl, S. *Children's voices: the views of vulnerable children on their service providers and the relevance of services they receive.* British Journal of Social Work, 36, 21-39, (2006) .

These authors tried to establish effective strategies that have been used in interviewing vulnerable children through a review of existing literature. They found that few studies that focus on interviewing young children are designed to address effectiveness. They found evidence to support the view that interviews with children aged under twelve are enhanced by the use of activity-based techniques as well as verbal assessment tools and that children enjoy computer-based assessment. It was found that children as young as three, four or five years can participate successfully in interviews, though the responses are affected by question format and age, gender and family circumstances can also be factors.

Part IV.
Materials and methodologies with a proven record in the area

As mentioned earlier in this review, researchers and other people who consult with children and young people with disabilities have developed a range of materials to facilitate the process. Publications detailing these methods (e.g. Morris 1998, Grove 1999, Marchant and Gordon 2001, Morris 2002,) stress however, that the value base, the planning of the consultation, the recognizing and tackling of barriers, and the choosing of the approach to communication are fundamental, and no 'method' will be effective unless these other aspects of the process are adequately thought out. In this section of the review, we draw attention to some of the points made by these authors and provide references to handbooks and toolkits which give details of communication methods which have been found to be successful at different stages of the process.

Setting up the visit

Morris (2002) has written a very comprehensive guide for those working with disabled children and young people with communication impairments. She details the barriers faced by children and young people with communication impairments - as identified by young people themselves and by their parents - reminding us, for example, that children who have communication impairments often experience very low levels of interaction (verbal and non-verbal) from other children and adults and that when children are treated as if they cannot communicate they sometimes 'switch off'. Further barriers to communication which should be taken into account are discussed in this publication, but the overall conclusion is that these children and 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.

Building relationships is part of the process. Caldwell (2000) and Edge (2001) are cited in Morris 2002 for ideas about the potential for people with high support needs to be involved in decisions about their lives and for ideas about how to build relationships with people with significant cognitive impairments and/or autistic spectrum disorder. Morris (2002) provides a list of behaviours which it has been suggested are 'indicators of communicative intent'. These 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.

Morris deals in detail with the process of getting to know the child or young person, including the role of parents and other family members, teachers, friends, advocates and interpreters. She gives advice on setting up and managing the interview, (some writers prefer to refer to the interview as a 'visit') and lists other important things to think about when meeting with the young person. In terms of the actual communication, she discusses:
* Using sign language,
* Using jargon (making it possible for a young person to communicate about something they don't like or which they are unhappy or angry about).
She also brings up the role of the speech and language therapist.

In a further section, Morris makes a number of useful points for those involved in helping a young person realize and operationalise their human right to communication - an objective which might be included in the duties of the SSI. She 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.

It 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.

Finally she quotes a social worker who advised:
'What is most important is to believe in the young person's potential or actual ability and to have on-going expectations of them. They need to know you have a genuine interest in getting to know them, in establishing communication with them and making a difference in their lives'.
This publication has an extensive list of helpful agencies, publications and resources.

Lessons learnt from experiences in setting up and carrying out consultations

An earlier publication by Morris (1998) explains how she and her co-researchers set about the challenge of seriously seeking the views and experiences of 30 disabled young people many of whom were described as having severe communication and/or cognitive impairments. It describes in detail the practicalities of going about this kind of work and shares the experience accumulated around issues like gaining consent, planning visits, using facilitators, equipment and communication aids, spending time with young people in order to find out more about their experiences, and so on. It also describes how the project went about establishing a reference group of young people who could advise the researchers as things progressed. The report summarises the lessons learnt by the project in seeking to gain the views of disabled children and young people about their lives and experiences, and it was felt that these lessons are equally relevant to those practitioners and agencies who are trying to ascertain the wishes and feelings of the disabled children with whom they are involved.
Factors which helped the process were identified as follows:
•   The preparation for the visits,
•   Not having tight deadlines,
•   Having the possibility of doing more than one visit,
•   Children's involvement in writing and structuring the information schedule,
•   Flexibility about how the information schedule was used,
•   Opportunities to be reflective about the process.
A checklist is provided of important points to bear in mind when finding out about the experiences of disabled children and young people.

Checklist (adapted from Morris, 1998)

- Start from the position that everyone can communicate.
- Recognise how much may need to be learnt to maximize meaningful communication with particular individuals.
- Assume nothing.
- Make contact with someone who knows the young person well and who likes and respects them. Try to ensure that information from others is treated as additional information about the young person rather than as a substitute for gathering information direct from them.
- Don't give up - be dogged in trying to make contact, setting up visits.
- Be flexible - say you can come any time, weekends, evenings, not just weekdays.
- Be prepared for carefully laid plans to go awry; try again; have a back-up plan.
- Allow lots of time for setting up the visit, and for visiting more than once.
- Be prepared for equipment to be broken down, for communication boards/books to be unavailable, or for them to be less than adequate for facilitating communication.
- Recognise the impact of prejudice and discrimination when you go into a residential establishment and that you may find it a very oppressive experience. Acknowledge this in your interview notes.
- Try to think about what it might feel like to be asked about things when you're not used to being asked, especially by a stranger.
- Don't allow the information schedule to constrain what you ask, how you ask it, in what order etc.
- Be prepared to make compromises in terms of how much information you can get from or about a participant.
- Recognise that you probably don't know much about the impairments experienced by the young people.
- Don't feel bad about making mistakes.
- Don't feel bad about not understanding when someone is trying to tell you something.
- Have a forum for talking about your experiences e.g. meeting together as inspectors.
- Send a 'thank you' card to each person visited.
- Ensure that the research budget includes enough resources for:
    - The time it takes to set up visits,
    - The additional training that may be required of inspectors,
    - The additional costs of facilitating communication,
    - Follow-up advice and information to those visited if they so wish.
- Think about how the findings of the inspection can be disseminated to young disabled people in a form which is of interest and accessible to them.

Communication approaches

Marchant and Gordon (2001), on behalf of Triangle, NSPCC and the Joseph Rowntree Foundation, produced *Two-Way Street: a communication handbook with a training video*. It includes short sections on background, value base, language audience, and the aims of the publication - which were to increase confidence and competence by:

- Reflecting on how the common myths and perceptions about disability impede and inhibit communication,
- Teaching and modelling good practice in establishing communication,
- Demonstrating specific options and giving clear summary information about the more commonly used augmentative and alternative methods,
- Reflecting on some common anxieties and 'mistakes' and ways to repair breakdowns in communication,
- Asserting the rights of disabled children to be listened to however they communicate.

The publication gives details about how the handbook was developed, and tips for planning and preparation, choosing communication approaches and writing up.

The following communication options are summarized and references are provided of sources for further information for each one: (N.B. some of these will *not* be relevant for the Irish situation - for example, Irish Sign Language differs in some respects from British Sign Language. Finding out the communication approaches used, by and with individual children is, therefore, of great importance).

> BSL British Sign Language,
> Blissymbolics,
> Braille,
> Chailey Communication System,
> Cued Speech,
> Deaf Blind Manual Alphabet,
> Fingerspelling,
> Lipreading,
> Makaton Language Programme,
> Mayer Johnson PCS Symbols,
> Moon,
> Objects of Reference,
> Paget-Gorman Signed Speech,
> PECS Picture Exchange Communication System,
> Photographs,
> Signalong,
> SE Signed English,
> Symbols.

Toolkits

The report by Turner (2003) (see part III) on the views of disabled children and young people in Wales includes a list of materials and resources used in the study. The materials are available from the project office and are as follows:
- 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.

This report also contains helpful pointers in an appendix related to:
Setting up groups and interviews - This includes advice on the time factor and the production of user-friendly and accessible information sheets for all concerned, as well as advice on taking into account factors that can impact on the process such as changes of staff, changes of routine, holidays, time, and resources.

Expressing opinions for the first time - This can mean that the children and young people struggle to give reasons why they like or dislike elements of a service or staff. They want to participate in decisions about their individual care and treatment and the services they use but often lack experience and support in the participation process.

Attitudinal barriers - In the majority of services staff and parents were supportive, but some showed reluctance to approach disabled children and young people about getting involved. It seemed to the researchers at times that it was not the physical or medical conditions that excluded disabled children and young people but the attitudes of people involved in their lives. The children least likely to be involved are those with severe learning disabilities, short attention spans and challenging behaviours. This is not based on any resistance to consulting children in general but perhaps more a difficulty in believing that more severely disabled children can make a contribution, or being at a loss to know how to make this happen.

The involvement of others - Few interviews took place with just the researcher and the child or young person. In many cases having another person present - a member of staff or a family member - gave the researchers support with interpretation particularly where children and young people could not communicate verbally. In addition they were able to help identify professionals and services received by the child or young person. In a minority of cases the presence of another appeared to have a negative impact on the consultation process. The researchers faced situations where adults answered on behalf of the child or young person, challenged what they had to say, or showed disapproval. At times it was felt that children and young people were censoring what they had to say because adults were listening in.

Talking to 'strangers' - Researchers had a relatively short time to get to know children and young people. Feedback from the consultation process suggested that it is crucial to set aside time for introductions and that when the same researcher returned to a service several times the consultation appeared to be more effective.

The environment - It was found important to meet children and young people in a wide variety of environments, in spite of the potential for distractions and interruptions, and on occasions to carry out informal discussions while joining in other activities with them.

The challenges in trying to consult with a wide range of ages and abilities - This project found it difficult to make contact with black and ethnic minority groups who constituted just 2% of their sample. They also carried out some consultation work with disabled children aged 8 years and under (22% of their sample) and suggest that this could usefully be built upon.

Part V.
Other methods identified in practice

In this section we summarise elements from a number of recent, very focused small-scale studies in which the methods used are considered to be relevant to this review. Full details are in the references section.

ISPCC (Irish Society for the Prevention of Cruelty to Children) for the NDA (2006) *A study of the impact of childhood disability on family dynamics.*

Preece, D (2002) *Consultation with children with autistic spectrum disorders about their experience of short-term residential care.*

Beresford, B, Tozer, R, Rabiee, P, and Sloper, P (2004) *Developing an approach to involving children with autistic spectrum disorders in a social care research project.*

Brewster, S.J (2004) *Putting words into their mouths? Interviewing people with learning disabilities and little/no speech.*

Germain, R (2004) *An exploratory study using cameras and Talking Mats to access the views of young people with learning disabilities on their out-of-school activi*ties.

ISPCC/NDA (2006)

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.

Preece, D (2002) *Consultation with children with autistic spectrum disorders about their experience of short-term residential care.*

The characteristics presented by children with autistic spectrum disorders were identified in this paper as affecting their ability to engage in consultation. These include factors such as:
- They have little intrinsic motivation to communicate or interact,
- They have difficulties comprehending abstract concepts such as emotion, space and time,
- Their understanding of language is affected by:
  - The amount of language used,
  - The overall stimulation level of the environment,
  - The context.
- They use language differently (where they use it at all) both from normally developing children and from children with learning disabilities or specific language impairments, and their communicative abilities and comprehension skills may be overestimated.

This study focused on four broad areas of investigation:
- The child's level of consultation and involvement,
- Activities available to them,
- The quality of care that they received,
- Their enjoyment of short-term care.

Three children were involved in the study. Two of them (boys aged 7 and 14) had some speech but also used other communication resources including photographs, picture symbols and objects of reference. The third child (a boy aged 12) had no speech and found interaction very stressful. His communication was extremely restricted, mostly comprising motoric gestures. It has been suggested that for practical and ethical reasons such children are most appropriately included in research/inspections by 'being with them'.

The range of utilised data collection techniques 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.

Data was collected in all three case studies regarding:
- The consultation process and its effectiveness,
- The child's ability to participate in the process,
- The child's experience of short-term care.

This was examined to assess the impacts of the 'triad of impairments' - in social interaction, in communication, and in the need for routine and resistance to change. A core of common issues was discerned across the three case studies:

- The characteristic impairments of autistic spectrum disorders (ASD) impacted upon all three children's abilities to participate in the consultation process,
- 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,
- The children's 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 cognizant of each child's individual cognitive, social and communicative abilities.

Beresford, B, Tozer, R, Rabiee, P and Sloper, P (2004) *Developing an approach to involving children with autistic spectrum disorders in a social care research project.*

As in the Preece study, this project drew on a number of 'data sources' with reference to each of the five children involved, informed by the Mosaic approach. These included:

- 'Interviews' with the children - where alleviating social anxiety and ensuring that the questions asked were meaningful were key concerns. Strategies included:
  - Social Stories - prepared individually for each child and used by the parent a number of times before the visit of the researcher. These provided detailed step-by-step information about why a situation is happening and what will happen, interspersed with gentle advice about how to react,
  - Using a familiar craft-making activity as the focus of the session, thus minimising direct face-to-face interaction between the child and the consulter/researcher,
  - Using photographs taken by the child,
  - Restricting the conversation to concrete here-and-now experiences.
- Interviews with parents and 'other informants'. The interviews with parents focused on desired outcomes for the child. Those with teachers were restricted to those areas of the child's life that the informant knew and felt comfortable discussing.
- Informal observation. The observations were on areas arising from parents' interviews - evidence of favoured activities, social interaction, opportunities to make choices, and experiences of success. They provided contextual data to parents' and teachers' accounts.

Significantly, it was noted that there was a strong sense that had it been possible, a repeat visit or visits would have allowed further exploration with the children about their lives.

Brewster, S.J (2004) *Putting words into their mouths? Interviewing people with learning disabilities and little/no speech.*

This paper discusses the issues involved in using one technique used to support interviewing with people with learning disabilities who are unable to speak - Talking Mats. This technique, in common with many techniques which augment communication, relies on someone else selecting the vocabulary to be made available. The technique involves physically moving graphic symbols around on a mat to facilitate discussion of a topic (Murphy and Cameron 2002). It includes three sets of picture symbols:
- Topics - Whatever needs to be talked about (e.g. pictures symbolizing what you want to do during the day, where you want to live, who you want to spend time with, communication in shops with strangers),
- Options pertaining to the situation,
- Visual scale of emotions - to allow the participant to indicate their general feelings about each topic and option: e.g. whether they are happy, unsure, or unhappy.

The issues (addressed in this paper) are how vocabulary is selected, the importance of involving peers, and the danger of circularity - that vocabulary may only be selected for communication about topics that the user can already communicate.

Germain, R (2004) *An exploratory study using cameras and Talking Mats to access the views of young people with learning disabilities on their out-of-school activities.*

This study was carried out with nine 16 year olds in a special school who all had statements of Special Educational Need for moderate or severe learning difficulties. They all had some spoken language ranging from giving single word answers to speaking in fuller sentences. Participants were given disposable cameras and asked to take photographs of their activities during half-term week. They were then asked to place the photographs under the appropriate symbol representing how they felt about the activity in the photograph - smiley, unsure or unhappy. Two days later, four of the participants were asked to repeat the process to check for understanding of the symbols and validity of the method. There were few changes made on the second sorting (92% similar placings).

A number of methodological, ethical and practical issues were identified, some of them beyond the control of the researcher. It was concluded, however, that this was a useful method of accessing the views of young people about their out-of-school activities, and that it would merit further development.

Part VI.
Points for reflection

It would seem, from the reports available, that the Inspectorate is currently adopting child-friendly approaches to its work. This paper has presented a discussion of issues for their consideration in extending their services to planning and undertaking consultation with children and young people with disabilities in residential care. It has included summaries of salient points from reports of this kind of work recently carried out in the United Kingdom and a menu of methodologies which have been found to be effective in eliciting the views and experiences of young people with learning and communication difficulties.

Initial reaction to the information provided proposed the following points of which inspectors should take note:

- Communication with children during inspections is not only about communication but also about understanding - ensuring a common understanding of constructs such as standards, the process of research and inspection, the residential centre and its role, and the possibility of change.

- Levels of articulateness vary considerably among the groups described in this review. There could be many reasons for this, including some that relate to the child's innate disposition and abilities/disabilities and the context in which s/he is living. In line with the focus of inspections, inspectors should consider the possibility that children who are not articulate have not been supported or encouraged to express their views within the care setting.

- Levels of articulateness can also depend on levels of information provided to the child in an accessible way. If it appears that information on particular issues has not been given to the child - for example, about his or her disability/possible future prognosis - it may also be the case that information has not been provided in other areas relevant to day-to-day living on which he or she might have a view.

- These two points lead into the question of a child's rights to communication - an issue which inspectors might identify as one to follow up in interviews. Are children aware of these rights, and are these rights being supported and promoted in the care environment?

- The question of reliability should be considered in the light of the aims of the inspection - if these include recording the perceptions of the child about his/her experiences, the emphasis should be on ensuring that the views of the child are being interpreted as the child wishes. In some cases there may be a need to seek other forms of evidence, but the views of the child should always be the starting point.

- Consideration should be given to the impact of meeting children with more severe disabilities or life-threatening conditions. Obviously modifications to the interview protocol will be needed . This issue could be linked with the recommendation emerging from a number of the reports reviewed - the need to know some details about the child in advance of the meeting/visit.

- The employment of an advocate or interpreter has been found to be effective. Usually it is not the primary caregiver, but a teacher, a peer or an adult friend and sometimes, depending on the circumstances, a parent. The child is always consulted.

- The communication passport referred to in the Harrison, Tucket and Simon (2004) study was thought to be worth trying as it would link into the general principle that the communication between inspectors and children with disabilities is not a one-off, but rather one situation in many where the child's communication skills are developed. The passport could provide continuity between the different individuals significant to the child, support them in communicating with the child, and also provide a way of measuring the child's development.

- The Inspectorate may wish to consider some variation in its ways of working with children when accessing children with disabilities. This might include the provision of more time per visit, of more visits per inspection, and of developing a variety of means of eliciting views such as questionnaires, visual materials etc. In some cases it may be necessary to use the services of an interpreter or to have training in augmentative and assistive communication methods for a member of the team.

Conclusion

We would envisage the production of a handbook or guidelines outlining methods and the consideration of issues to be developed in consultation with children and young people which would support the inspectors in their work. We would envisage further discussion on specific methodologies for use with children and young people with disabilities - depending on the nature of the information required from the children and their levels of communication competence. We would recommend that contact be established with some of the organizations in the UK who have been working in this area with a view to determining whether it would be worthwhile accessing their expertise in perhaps a one-day workshop addressing specific questions.

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Part VII.
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Part VIII.
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